# Children with complex special health care needs and the health services system: Unmet needs, barriers to care, and coordination of health services.

by

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# Chapter 1. Introduction

*Who are Children with Special Health Care Needs?* As a result of improvements in perinatal technology and the treatment of childhood trauma and disease there has been an increase in survival rates for children who are severely ill. Consequently, children have the highest growth rate of disability of any population cohort (Perrin, 2002). To facilitate research and policy relating to this diverse group of children the U.S. Maternal and Child Health Bureau has defined children with special health care needs (CSHCN) as having chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required by children generally (van Dyck et al., 2002). Based on this definition, a 2005 nationally representative survey identified fourteen percent of American children as having special health care needs (Data Resource Center for Child & Adolescent Health, 2008). This is a utilization based, rather than condition specific, definition and as such encompasses a variety of conditions. Within and between conditions children vary in their disease complexity and functioning limitations. This heterogeneous population results in a continuum of disease severity including both children with controlled asthma and quadriplegics dependent on mechanical ventilation to sustain the basic life function of breathing.

*High Complexity CSHCN as a Distinct Subgroup.* The broad objective of this dissertation research is to examine the health care system experiences of a vulnerable population: children with complex special health care needs. While there is no accepted

definition of the term "complex health care needs," it is generally considered to be a function of the child's ongoing healthcare needs, including the required number of providers, the diversity of types of providers, and the frequency of provider contacts (Agency for Healthcare Research and Quality, 2008; Bramlett, Read, Bethell, & Blumberg, 2008; Kirk, 2008). Among the adult population most people who receive the label of "high complexity" report multiple chronic conditions, frequent hospitalizations, and functional limitations (Bodenheimer & Berry-Millet, 2009). Studies of CSHCN have operationalized "complex health care needs" as the number of health consequences based on the CSHCN screener, functioning limitations, condition severity, co morbidities, school absences, number of different types of services needed, stability of the child's condition, number of emergency department visits and multiple combinations of these variables (Antonelli & Antonelli, 2004; Benedict, 2008; Bramlett et al., 2008; Dusing, Skinner, & Mayer, 2004; Fulda, Lykens, Bae, & Singh, 2009; Ganz & Tendulkar, 2006; Inkelas, Raghavan, Larson, Kuo, & Ortega, 2007; Kuhlthau, Hill, Yucel, & Perrin, 2005; Mayer, Skinner, & Slifkin, 2004; Mulvihill et al., 2005; Nageswaran et al., 2008; Nageswaran, Silver, & Stein, 2008; Oswald, Bodurtha, Willis, & Moore, 2007; van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004; Warfield & Gulley, 2006).

Despite the lack of a consistent operationalization of complexity, children with "complex medical needs" report a high level of unmet needs and access barriers. For example, among a nationally representative sample of children with special health care needs (CSHCN), 27% of children with the most severe, complex needs reported an unmet need for health services (Bramlett et al., 2008) and 40% reported that services were not easy to use (Nageswaran et al., 2008), compared to 6% and 16% respectively, of low

complexity CSHCN. These high complexity CSHCN also use the majority of the health care resources directed toward CSHCN (P. W. Newacheck, Inkelas, & Kim, 2004). Although previous studies have found that severe, complex health care needs are consistent, independent predictors of negative outcomes (including unmet need for medical, therapeutic and/or mental health services, barriers to care, lack of care coordination, and negative financial impacts on the family) (Benedict, 2008; Dusing et al., 2004; Ganz & Tendulkar, 2006; Inkelas et al., 2007; Inkelas et al., 2007; Kane, Zotti, & Rosenberg, 2005; Nageswaran et al., 2008), important questions that are integral to developing policy solutions remain unanswered. Specifically, how do we identify this group of children? What is their demographic and health status profile? What specific access barriers do these children face and what aspects of the health system may improve access among this group? Chapters 2 through 4 in this dissertation have methodological and empirical aims designed to address these questions, with the goal of informing policy discussions surrounding children with complex health care needs and how the health care system can best meet their needs.

Chapter 2 focuses on a gap in the state of research regarding identification of the high complexity subgroup of CSHCN, and explores two research questions: (1) how well does a small set of variables represent the latent construct of highly complex health care needs within the population of CSHCN?; (2) how do the demographic profile and health services needs of children with highly complex health care needs differ from that of children with low to moderate complexity special health care needs? To examine these questions I analyze a nationally representative data set of CSHCN, the 2005 National Survey of Children with Special Health Care Needs (NS-CSHCN) (Blumberg et al.,

2008). First I conduct a factor analysis of eight variables previously used to measure complexity, in search of an efficient and valid set of variables to measure the latent construct of high complexity to address Research Question 1. I then use this measure to identify high complexity CSHCN and compare the demographics, unmet needs and barriers to care reported by this group to low to moderate complexity CSHCN. The main thesis of the first paper is that children on the complex end of the CSHCN continuum can be identified by a short complexity measure and these children have needs that differ markedly from the broader group and as such should be the focus of independent studies and policy discussions.

Chapter 3 examines the role of care coordination in the health care experiences of children with complex health care needs. This population reports higher unmet need for health care services than the general population of CSHCN and care coordination has been proposed as a solution to reduce barriers to care among this population. I analyze the same dataset as Chapter 2 to explore three research questions: (1) what percentage of children with complex special health care needs receive adequate care coordination assistance and who provides this assistance? A description of the current level of care coordination for CSHCN is a necessary first step toward assessing the state of care coordination services in the U.S.; (2) what are the sociodemographic and health status correlates of reporting an unmet need for care coordination? Elucidating the factors that are associated with unmet need for care coordination assistance may reveal potential sites for intervention to improve access to care coordination; (3) what is the strength of the association between receipt of care coordination and parent reported unmet need? Specifically, I test the hypothesis that receiving coordinated health care is associated with

reductions in unmet needs for medical, therapeutic, and supportive services within the population of children with complex health care needs. Through the investigation of these three research questions this chapter presents a profile of care coordination services for children with complex health care needs and explores coordination as a policy solution to reduce unmet needs for care.

Chapter 4 will focus attention on a distinct, vulnerable group of technology dependent children. Due to advances in the medical field the population of children dependent on technology for basic life functions is growing. However, there is little known about the level of care that these unique children receive within the outpatient health care system. Chapter 3 addresses three research questions: (1) what is the demographic and health status profile of ventilator dependent children? This type of detailed information is necessary for program development and also to explore correlates of barriers and unmet needs; (2) what unmet needs for medical and therapeutic services do these families report and what access barriers do they face? Despite the risk factors inherent in the nature of these children's disabilities there is a lack of research on this topic; (3) what is the level of unmet need for care coordination assistance within a defined care coordination program and what variables are associated with this unmet need? If there is indeed a high level of unmet need among this population, care coordination assistance may be a way to ameliorate the barriers to care faced by this vulnerable population. The data collection instrument is a survey of the parents of children on ventilators who attend home ventilator clinic at a large major medical center. My goal for this chapter is to fill a gap in the research by describing the interaction between families with a ventilator dependent child and the health services system in order

to inform policy and practice at the study site and at the state and national level in regards to this specific ventilator dependent population, and also to inform broader questions about access to care and care coordination for the population of children with complex special health care needs.

In current policy discussions it is acknowledged that CSHCN are a heterogeneous group, however, policy prescriptions are aimed at this group as a whole. The main aim of this dissertation research is to frame children with complex health care needs as a distinct policy group. This dissertation makes methodological contributions to the research literature by developing and validating a measure of complexity of health care needs and employing this measure to identify the unmet needs and access barriers faced by the high complexity group with the dual aim of establishing these children as a unique sub-population of CSHCN and informing policy discussions surrounding children with complex health care needs and how the health care system can best meet these needs. The measure of complexity of health care needs developed and validated in this paper will provide future research with a consistent operationalization of complexity which can aid in further identifying the specific needs of this population and tailoring policy to meet those needs.

# Chapter 2. Development of a measure to identify and describe children with complex special health care needs.

Among the heterogeneous population of children with special health care needs (CSHCN) there is a vulnerable subpopulation who have complex medical needs that result in high intensity utilization of a diverse array of health services. These high complexity children report a high level of unmet needs and access barriers (Bramlett et al., 2008); (Nageswaran et al., 2008), despite using the majority of the health care resources directed toward CSHCN (P. W. Newacheck et al., 2004). In order to improve access to care for this group it is necessary to determine their demographic and health status profile and explore the specific access barriers faced by these children and their families. These are questions that have yet to be addressed in the literature.

Central to these gaps in the research is the lack of a consistent operationalization of the construct of complexity of medical needs within the population of children with special health care needs. While there is no accepted definition of the term "complex health care needs," it is generally considered to be a function of the child's ongoing healthcare needs, including the required number of providers, the diversity of types of providers, and the frequency of provider contacts (Agency for Healthcare Research and Quality, 2008; Bramlett et al., 2008; Kirk, 2008) . Among the adult population most people who receive the label of "high complexity" report multiple chronic conditions, frequent hospitalizations, and functional limitations (Bodenheimer & Berry-Millet,

2009). In studies of CHCN, "complex health care needs" has been operationalized by a number of variables including: the number of health consequences based on the CSHCN screener, functioning limitations, condition severity, co morbidities, school absences, number of different types of services needed, stability of the child's condition, number of emergency department visits and multiple combinations of these variables (Antonelli & Antonelli, 2004; Benedict, 2008; Bramlett et al., 2008; Dusing et al., 2004; Fulda et al., 2009; Ganz & Tendulkar, 2006; Inkelas et al., 2007; Kuhlthau et al., 2005; Mayer et al., 2004; Mulvihill et al., 2005; Nageswaran et al., 2008; Nageswaran et al., 2008; Oswald et al., 2007; van Dyck et al., 2004; Warfield & Gulley, 2006).

Table 2.1 is a list of selected articles, their outcome variables, and which of these eight variables were used to stratify CSHCN by complexity. In all of these studies focusing on different outcome variables, each of the complexity variables was associated with an increased likelihood of negative outcomes, though these factors were not the focus of many of these studies. It is an open question as to whether these variables are measuring one latent construct of complexity of health needs, or if these variables identify two separate groups—children with poor health status and children with complex service needs—both of which are associated with negative outcomes. Condition severity, stability of the child's condition, number of emergency department visits, and school absences could be viewed as measures of a child's health status whereas functioning limitations, co morbidities, and number of types of services needed appear to more directly measure the frequency of a child's service needs. However, the health status measures could also affect the rate of health service utilization and the frequency of

Table 2.1. Variables used in the literature to operationalize complexity when predicting negative health services outcomes

| | | Factor Analysis Variables | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Citation | Outcome Variables * | CSHCN Screener | Functioning Limitation | Severity/ Health Status | # of conditions | School Absences | # of Services Needed | Stability | ER Visits |
| Antonelli & Antonelli 2004 | Cost of un-reimbursable care coordination activities | | | | X | | | | |
| Benedict 2006 | Unmet need for therapeutic and supportive services | | X | X | | | | | |
| Bramlett et al. 2008 | Unmet need for services; Medical expenditures | X | | | | X | X | | X |
| Dusing et al. 2004 | Unmet need for therapy, assistive devices, and related services | | X | | | | | | |
| Fulda et al 2008 | Unmet need for a Medical Home | | X | | | | | | |
| Ganz & Tendulkar 2006 | Unmet need for mental health care | | | X | | | | X | |
| Inkelas et al. 2007 | Unmet need for mental health care | | X | | | | | X | |
| Kuhlthau et al. 2005 | Family financial burden | | X | X | | X | | | |
| Mayer et al. 2004 | Unmet need for routine and specialty care | | | X | | | | X | |
| Mulvihill et al. 2005 | Need for care coordination; unmet need for health services | X | X | X | | | | | |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Nageswaran et al. 2008 | Unmet need for health services; Care coordination; inadequate insurance | | X | | | | | | |
| Oswald et al. 2007 | Unmet need for a Medical Home; Dissatisfaction | | X | X | | | | X | |
| Van Dyke et al. 2004 | Unmet need for services; Dissatisfaction | | X | | | | | | |
| Warfield & Gulley 2006 | Unmet need for health services | | | X | | | X | X | |
| * For each article, there was a positive, significant association between the complexity variables and the negative outcome variables | | | | | | | | | |

service needs measures are certainly also indictors of health status.

It is possible that these variables represent one latent construct of complexity of special health care needs in which condition severity is inextricably linked to complexity of needs. Despite the lack of a consistent measure of complexity, previous research on the heterogeneous population of CSHCN has demonstrated that children with highly complex health needs – based on one or more of the variables in Table 2.1 – have a higher likelihood of negative outcomes than children whose needs are less complex (including unmet need for medical, therapeutic and/or mental health services, barriers to care, lack of care coordination, and negative financial impacts on the family) (Benedict, 2008; Dusing et al., 2004; Ganz & Tendulkar, 2006; Inkelas et al., 2007; Inkelas et al., 2007; Kane et al., 2005; Nageswaran et al., 2008). The level of unmet need for health care among CSHCN is relatively modest, 10% reported any unmet need for a variety of direct medical and supportive services (Bramlett et al., 2008); however, children with poor health status and multiple service needs (including functioning limitations, severe conditions, and/or multiple co morbidities) are overrepresented among the population with unmet needs (Huang, Kogan, Stella, & Strickland, 2005; Mayer et al., 2004; Nageswaran et al., 2008; van Dyck et al., 2004). Cross-sectional health economics research has shown that ten percent of the CSHCN population accounts for more than two-thirds of health care expenditures for CSHCN (P. W. Newacheck et al., 2004) and a longitudinal analysis found that children with poor health status have the greatest odds of persistently falling in that small high-cost group (Shenkman, Knapp, Sappington, Vogel, & Schatz, 2007). The persistent association between the most complex CSCHN, negative outcomes, and high expenditures leads to questions about the characteristics of

these high complexity children and how their needs may differ from the broader group. However, in the literature complexity of health needs is typically added to models to stratify or adjust the outcomes of interest. It is true that high complexity children are high utilizers and therefore present more opportunities for unmet needs, but this persistent association may also be the result of unique barriers to care faced by this population as a consequence of their complex health care needs. There is a gap regarding these children as the independent focus of policy and research.

This research focuses on addressing the gaps in the research outlined above by examining two research questions: (1) how well does a small set of variables represent the latent construct of highly complex health care needs within the population of CSHCN? and (2) how do the demographic profile and health services needs of children with highly complex health care needs differ from that of children with low to moderate complexity special health care needs? The goal of Research Question 2 is to explore the demographic and diagnostic profile of children with complex health care needs and elucidate the barriers to care and predictors of unmet need among this group. The main thesis of this chapter is that children on the complex end of the CSHCN continuum have needs that differ markedly from the broader group and as such should be the focus of independent studies and policy discussions.

## Research Design and Methods

**Data Source:** The data source was the 2005 National Survey of Children with Special Health Care Needs (2005 NS-CSHCN) – sponsored and funded by the U.S. Maternal and Child Health Bureau and fielded in 2005 to collect a nationally representative sample of CSHCN (Blumberg et al., 2008). Please refer to Blumberg et al.

(2008) for more extensive information on the design and operation of the 2005 NS-CSHCN. The survey contains the data on 40,723 CSHCN and for this analysis responses were weighted to represent the national population of CSHCN using the Taylor-series-approximation method in Stata 9. (For more details on the sampling weights see Blumberg et al. 2008).

**Methods:** *Factor Analysis Variables.* The high complexity subgroup was identified using the measure of complexity of health care needs developed from a factor analysis. There were seven variables available in the 2005 NS-CSHCN that have previously served, either separately or in various combinations, as measures of poor health status and service need when studying the effect of complexity on outcomes within the CSHCN population: number of qualifying screener conditions from the CSHCN Screener, severity of functioning limitations, number of health conditions reported, number of days of school missed due to illness, number of different types of services needed, number of ER visits, stability of the child's condition (See Table 2.1 for more details on the articles and citations). Condition severity and/or health status have also been used previously and are included in Table 2.1; however, the 2005 NS-CSHCN survey instrument does not contain a question regarding condition severity or health status, as separate from functioning limitations. However, many of the available variables are markers of both severity of health conditions and health services need. One goal of the factor analysis was to determine if these variables measured one latent construct of complexity of health care needs in which condition severity was linked to increased complexity.

"Screener count" - number of qualifying screener conditions - was based on responses to the CSHCN Screener which was developed to standardize the identification of CSHCN (Bethell et al., 2002). To qualify as having special health care needs, a child must currently experience one or more of five health consequences attributable to a medical, behavioral, or other health condition that has lasted or is expected to last for at least 12 months. These consequences include whether the child 1) is limited or prevented in any way in his or her ability to do things most children of the same age can do; 2) needs or uses medications prescribed by a doctor (other than vitamins); 3) needs or uses specialized therapies such as physical, occupational, or speech therapy; 4) has above-routine need or use of medical, mental health, or educational services; or 5) needs or receives treatment or counseling for an emotional, behavioral, or developmental problem. The 2005 NS-CSHCN variable "screener count" was a count of the number of qualifying health consequences, 1-5, reported on the CSHCN screener.

"Functioning limitations" was operationalized as a composite measure of the two questions "How often does the child's health condition affect his/her ability to do age-appropriate things: never, sometimes, usually, always?" and when this occurs "How much limitation does the child experience: very little, some, a great deal?" Functioning limitations was divided into 3 categories, severe, some, or no limitation based on the coding scheme from Nageswaran et al. (2008). If the response to the first question was never, then the child was coded as "no limitations." If the response to the first question was sometimes and the response to the second questions was some or very little, then the child was coded as "some limitation." If the response to the first question was usually or

always or the response to the second question was a great deal, then the child was coded as having "severe limitations".

The variable "Co morbidities" was based on a count of the number of conditions reported from a list of 16 health conditions. "Days of school missed" was based on responses to the question "Number of school days missed during the past 12 months due to illness or injury?" The 2005 NS-CSHCN asked parents if the child had a need in the past 12 months for 15 health and supportive services. "Number of services needed" was a count of the number of different types of services the child needed. "Number of ER visits" was drawn from the question, "During the past 12 months, how many times did your child visit a hospital emergency room?" Condition stability was measure by one question, "Do your child's health care needs change all the time, change once in awhile, or are usually stable?" with the response categories all the time, once in a while, and usually stable coded as 1,2, and 3 respectively.

*Demographics Variables.* Respondents provide the child's age, gender and ethnicity/race as well as household income level (coded as percent of the federal poverty level). A child was coded as having a usual source of primary care if the parent reported that there is a place the child goes when he/she needs routine preventive care AND the child has a personal doctor or nurse. Health insurance was coded as adequate if the parent reports that the child has public or private insurance at the time of the interview, the child had no gaps in coverage during the year before the interview, insurance usually or always meets the child's needs, costs not covered by insurance are usually or always reasonable, and insurance usually or always permits the child to see needed providers. This measure

of "adequate insurance" has been found to be inversely associated with unmet needs and negative outcomes in the CSHCN population (Oswald et al., 2007).

*Diagnoses.* The child's medical diagnoses were based on parent-report. Respondents were asked "To the best of your knowledge, does the child currently have any of the following: asthma; attention deficit disorder (ADD) or attention deficit hyperactive disorder (ADHD); autism or autism spectrum disorder (ASD); down syndrome; mental retardation or developmental delay; depression, anxiety, an eating disorder, or other emotional problems; diabetes; heart problems; blood problems; cystic fibrosis; cerebral palsy; muscular dystrophy; epilepsy or other seizure disorder; migraine or frequent headaches; arthritis or other joint problems; allergies. For the purpose of this study each diagnosis was a binary variable coded as 1 for each condition the parent reported.

*Barriers and Unmet Need.* The 2005 NS-CSHCN asked parents if the child had a need in the past 12 months for 15 health and supportive services. For each reported need the parent was asked, "Did the child receive all the (fill in the service) care that he/she needed?" For the purposes of this study a child was coded as having an unmet need for care if the parent reported "No" to this question. For each unmet need the parents were asked "Why did the child not get the (name the service) that he/she needed?" and asked to check all that apply from a list of 15 barriers to care and an "other" category. The main dependent variable was a bivariate measure of any unmet needs coded as 1 if the parent reported one or more unmet need and coded as 0 if no unmet needs were reported. Additional dependent variables were four categories of health care services: preventive care, specialty care, therapeutic services (occupational, physical, and speech therapy;

mental health; or substance abuse services), and supportive services (specialized equipment, transportation, home health, or respite care). Therapeutic and supportive services were defined as proposed by Benedict (2008). These binary variables were coded as 1 if the parent reported an unmet need within these four categories.

*Analysis.* To address Research Question 1 a principal axis common factor analysis was conducted on the seven available variables and the factor with an eigen value greater than 1 was retained (Pett, Lackey, & Sullivan, 2003). I then predicted a full model factor score, this score represented the respondents' predicted values for the factor and was calculated using the factor weights and the original variable values. I then conducted multivariate linear regression with the full model factor score as the dependent variable and only the variables that loaded significantly onto the factor (factor loading > 0.50, the threshold value of 0.5 has been commonly used (Pett et al., 2003)), as the independent variables. The set of variables that explained the majority of the variance in the factor score ($R^2$ >.70) were then inserted into a separate factor analysis and a factor score was generated from this small subset of variables. A Pearson's correlation between the two factor scores determined the strength of the correlation. Next, a series of bivariate logistic regressions were conducted to validate that the factor score created from the small subset of variables was associated with criterion variables in the same direction and magnitude as the full model factor score. The three criterion variables have been found in previous research to be significantly associated with the variables contained in the full model factor score: unmet need for services ((Huang et al., 2005; Mayer et al., 2004; Nageswaran et al., 2008; van Dyck et al., 2004), family financial problems related to the child's condition (Kuhlthau et al., 2005; Mulvihill et al., 2005), and inadequate

insurance coverage (Nageswaran et al., 2008). This newly developed measure was applied to the 2005 NS-CSHCN and children who scored on the severe end of the variables in the measure were included in the subgroup of high complexity CSHCN .

To explore Research Question 2 I present the demographic profile of both the high complexity subgroup and the full CSHCN sample and conduct bivariate tests for a significant difference in the means of the demographic variables by complexity. I also report the percentage of respondents who reported any unmet need and an unmet need for preventive care, specialty care, physical, occupational or speech therapy and home health care and conduct bivariate logistic regressions of a significant difference in levels of needs and unmet needs between the high complexity and low/moderate complexity subgroups of CSHN. The top three barriers to care for each of the four services are reported for both the high complexity and low/moderate complexity populations. All analyses were conducted using the complex survey design functions of Stata 9.2.

## Results

A correlation matrix between the seven variables previously used to measure complexity (number of qualifying screener conditions from the CSHCN Screener, severity of functioning limitations, number of health conditions reported, number of days of school missed due to illness, number of different types of services needed, number of ER visits, stability of the child's condition) revealed correlation coefficients between 0.14 and 0.54. Table 2.2 presents the results of a principle axis common factor analysis of these seven variables. There was one significant factor with an eigen value of 1.93, the next highest eigen value is 0.26. There was no need to rotate the factor matrix because only one factor had an eigen value above the cut-off point of 1.00. Screener count and

functioning limitations had factor loadings above 0.60, with forty to fifty percent of the variability in each variable explained by the factor (Commonality 0.50 and 0.40). The other five variables had factor loadings between 0.36 and 0.57, with between twenty and thirty percent of each variable's variability explained by the factor (Commonality between 0.22 and 0.32). None of the seven variables had a factor loading above 0.30 on any other factor.

Table 2.2. Factor Analysis of seven variables previously used to measure complexity
Principal Component Common Factor Analysis

| | Factor 1 | Factor 2 | Factor 3 | Commonality |
|---|---|---|---|---|
| Eigen Value | **1.9259** | 0.2641 | 0.0249 | |
| screener count | **0.6620** | -0.2504 | 0.0179 | 0.5013 |
| functioning limitations | **0.6083** | -0.1476 | -0.1212 | 0.3980 |
| # of co morbidities | **0.5684** | -0.0286 | -0.0021 | 0.3239 |
| days of school missed | 0.4814 | 0.2763 | 0.0058 | 0.3081 |
| # of services needed | 0.4559 | -0.0251 | 0.1276 | 0.2342 |
| number of ER visits | 0.4747 | 0.0827 | -0.0453 | 0.2366 |
| condition stability | 0.3601 | 0.3082 | -0.0060 | 0.2247 |

Note. Bold denotes an eigen value of > 1 or a factor score > 0.50

A factor score for the full model was generated and a regression on the two variables with factor loadings above 0.60 revealed that 74% of the variance in the seven variable factor score was explained by screener count and functioning limitations (adjusted R-squared of 0.74). The co morbidity variable had a factor loading just above the 0.50 cut off. For exploratory purposes a multivariate linear regression was conducted on these three variables and the addition of co morbidities explained an additional 10% of the variance (adjusted R-squared of 0.84). The purpose of this analysis was to develop a set of variables that represent a parsimonious and replicable measure of complexity; the

co morbidity variable was created by summing the number of conditions reported out of a list of 16 conditions, therefore, a series of sixteen questions must be added to a future survey to generate this variable. The increased variance explained by this third variable does not outweigh the added costs to the replicability and parsimony of adding this variable to the complexity measure. Therefore, two variables were retained and a principal axis common factor analysis of these two variables was conducted to predict a score for the reduced model. The correlation coefficient between the full model and reduced model was 0.86. Table 2.3 presents bivariate logistic regressions of the full and reduced model scores on the three criterion variables. For both the full and reduced model, a higher complexity score is associated with a 2.22 (95% CI 2.08-2.37)) and 2.23 (95% CI 2.10-2.37), respectively, increase in the likelihood of reporting an unmet need for services ($p = 0.000$), a 1.42 (95% CI 1.35-1.50) and 1.45 (95% CI 1.38-1.52) increase in the likelihood of reporting inadequate insurance ($p = 0.000$), and a 2.71 (95% CI 2.53-2.91) and 2.91 (95% CI 2.74-3.08) increase in the likelihood of reporting financial problems resulting from the child's condition ($p = 0.000$).

Table 2.3. Associations between Criterion Variables and the Full and Reduced Model

| Bivariate Logistic Regressions | Unmet Need | | | Inadequate Insurance | | | Financial Problems | | |
|---|---|---|---|---|---|---|---|---|---|
| | Odds Ratio | 95% C.I. | | Odds Ratio | 95% C.I. | | Odds Ratio | 95% C.I. | |
| Full Model Score | 2.22 | (2.08-2.37) | *** | 1.42 | (1.35-1.50) | *** | 2.71 | (2.53-2.91) | *** |
| Reduced Model Score | 2.23 | (2.10-2.37) | *** | 1.45 | (1.38-1.52) | *** | 2.91 | (2.74-3.08) | *** |

Note:* $p<0.05$, ** $p<0.01$, *** $p<0.001$. Full model score includes all eight complexity variables. Reduced model score includes screener count and functioning limitations. Scores calculated from two separate principal axis common factor analyses.

The two-variable measure of complexity developed from the factor analysis was applied to the 2005 NS-CSHCN in order to identify the national population of children with complex health care needs. Screener count, the first variable in the measure, was a count of the number of qualifying health consequences, 1-5, reported on the CSHCN screener. A greater number of qualifying screener consequences had been found to be associated with poorer health status and a greater frequency of needs and unmet needs, with a consistent significant difference between 1-3 and 4/5 consequences (Bramlett et al., 2008). 11.5% of respondents reported 4 or 5 health consequences. The second variable included in the complexity measure was functioning limitations. 22.7% of respondents reported their child had severe functioning limitations (38.8% some limitations, 38.5% no limitations). Complexity was coded as 1 if the respondent reported 4 or 5 qualifying health consequences on the CSHCN screener *and* reported severe functioning limitations. Based on this operationalization, 3,586 children (8.8%) in the dataset fall into the high complexity category (117 respondents, 0.29%, are coded as missing due to missing data for at least one of the two variables).

Table 2.4 compares the demographic and diagnostic profile of the high complexity population outlined above to the remaining CSHCN population. High complexity CSHCN were significantly more likely to be poor, male, and lack adequate insurance ($p < 0.000$). 24.8% of high complexity CSHCN had unstable health care needs versus 4.5% of low to moderate complexity CSHCN ($p < 0.000$). High complexity CSHCN also reported significantly more co morbidities (3.1 versus 1.7, $p < 0.000$), school absences due to illness (6.8 versus 4.2, $p < 0.000$), types of services needed (6.4 versus 4.5, $p <0.000$) and ER visits (1.4 versus 0.8, $p < 0.00$). Regarding specific health

conditions, high complexity children had a significantly higher likelihood of being diagnosed with 13 of the 16 disorders queried ($p < 0.000$). There was no significant difference between the rate for diabetes and cystic fibrosis which were very low prevalence disorders, and allergies, which was reported by half of all CSHCN (50.4% of high complexity CSHCN and 53.3% of low/moderate complexity CSHCN). The largest differences in diagnosis rates by complexity were for a diagnosis of autism (30.5% high complexity versus 3.1% low to moderate complexity, $p<0.000$), mental retardation (57.2% high complexity versus 7.1% low/moderate complexity, $p <0.000$), mental health problems (52.6% high versus 18.1% low/moderate) and cerebral palsy (11.8% versus 0.9%, $p < 0.000$). Asthma was significantly more likely among the low to moderate complexity group (25.3% high complexity versus 40.1% low/moderate complexity, $p <0.000$).

Table 2.4. Descriptive report of the population of children with complex health care needs compared to the population of children whose special health care needs were not complex.

| | High complexity CSHCN | Low/Moderate Complexity Population | |
|---|---|---|---|
| Unweighted number of respondents | 3,586 | 37,020 | |
| Weighted percentage of CSHCN | 8.8% | 91.2% | |
| **Demographics** | | | |
| *Child Age* | | | |
| 0-5 years old | 20.9% | 20.9% | |
| 6-11 years old | 39.5% | 37.1% | |
| 12-17 years old | 39.6% | 42.0% | |
| *Child Ethnicity* | | | |
| White, non-Hispanic | 65.3% | 65.2% | |
| Hispanic | 13.6% | 11.4% | |
| Black/African-American | 13.9% | 16.7% | |
| Multi racial, Other (including Asian) | 7.1% | 6.7% | |
| *Child Gender* | | | |
| Male | 65.4% | 58.8% | * |

| | | | |
|---|---|---|---|
| Female | 34.6% | 41.3% | |
| *Household Income (% FPL)* | | | |
| < 100 % | 26.3% | 19.1% | * |
| 100-200 % | 26.7% | 21.6% | |
| 200-400 % | 26.7% | 30.0% | |
| > 400 % | 20.3% | 29.3% | |
| No usual source of primary care | 10.7% | 12.4% | |
| Inadequate insurance | 48.7% | 36.9% | * |
| | | | |
| **Alternate measures of complexity, past year** | | | |
| Child's health care needs are unstable | 24.8% | 4.5% | * |
| Number of health conditions reported | 3.1 | 1.7 | * |
| Number of school absences due to illness | 6.8 | 4.2 | * |
| Number of types of services needed | 6.4 | 4.5 | * |
| Number of ER visits | 1.4 | 0.8 | * |
| | | | |
| **Diagnoses** | | | |
| Asthma | 25.3% | 40.1% | * |
| Attention Deficit Disorder (ADD or ADHD) | 52.5% | 27.8% | * |
| Autism or Autism Spectrum Disorder (ASD) | 30.5% | 3.1% | * |
| Down Syndrome | 5.5% | 0.5% | * |
| Mental retardation or developmental delay | 57.2% | 7.1% | * |
| Mental Health problems | 52.6% | 18.1% | * |
| Diabetes | 1.3% | 1.6% | |
| Heart problems | 7.5% | 3.2% | * |
| Blood problems | 4.4% | 2.2% | * |
| Cystic Fibrosis | 0.6% | 0.3% | |
| Cerebral Palsy | 11.8% | 0.9% | * |
| Muscular Dystrophy | 1.2% | 0.3% | * |
| Epilepsy or other seizure disorder | 16.2% | 2.3% | * |
| Migraine or frequent headaches | 22.3% | 14.5% | * |
| Arthritis or other joint problems | 12.5% | 3.5% | * |
| Allergies | 50.4% | 53.3% | |

Notes: Data from the 2005 National Survey of Children with Special Health Care Needs; All values are percentages weighted to reflect the national population of CSHCN, except under the "alternate measures of complexity" subhead where means are reported; asterisk indicates levels of the independent variables are significantly different by complexity ($p < 0.000$).

Table 2.5 presents the prevalence of need and unmet need for health and supportive services among high complexity CSHCN and the remaining CHSCN

population. High complexity CSHCN were significantly more likely to report a need for services and among those who reported a need, they were significantly more likely to report unmet needs ($p < 0.01$). 27.4% of high complexity CSHCN reported unmet needs for care compared to 9.0% of the low to moderate complexity population. Among highly complex children the highest level of unmet need was for therapeutic services, 21.8%, followed by supportive services, 15.5%. The greatest difference in unmet need by complexity was for supportive services; 15.5% versus 4.5% ($p < 0.000$). A multivariate logistic regression was conducted to determine independent associations between demographic variables and unmet need for care (results not presented in tables). Controlling for inadequate insurance, poverty, age, race and gender, the odds of reporting an unmet need for care was 3.32 times greater for high complexity children ($p < 0.000$, 95% CI 2.85-3.88). This odds ratio was higher than for inadequate insurance (OR = 3.14, 95% CI 2.75-3.59) and poverty (OR = 1.46, 95% CI 1.38-1.55).

Table 2.5. Prevalence of needs and unmet needs among high and low/moderate complexity Children with Special Health Care Needs.

| | High complexity CSHCN | Low/Moderate Complexity CSHCN | |
|---|---|---|---|
| **Prevalence of needs and unmet needs** | | | |
| Need for preventive care | 82.1% | 77.3% | * |
| Need for specialty care | 76.1% | 49.3% | * |
| Need for therapeutic services | 94.5% | 34.9% | * |
| Need for supportive services | 52.0% | 24.3% | * |
| *Unmet need among CSHCN reporting a need* | | | |
| Any unmet needs | 27.4% | 9.0% | * |
| Unmet need for preventive care | 4.0% | 2.3% | * |
| Unmet need for specialty care | 9.1% | 4.8% | * |
| Unmet needs for therapeutic services | 21.8% | 14.4% | * |
| Unmet needs for supportive services | 15.5% | 4.5% | * |

Notes: All values are percentages weighted to reflect the national population of CSHCN; asterisk indicates levels of the independent variables are significantly different by complexity ($p < 0.01$).

Table 2.6 presents the top three barriers to care reported for routine preventive care, specialty care, and therapy. Among the high complexity group the top three barriers to routine preventive care where "not convenient times," "cost too much", and "doctor didn't know how to treat." For specialty care the high complexity population reported "cost too much," "not available in area/transportation," and "health plan problems." Among the low to moderate complexity CSHCN population financial barriers – "no insurance," "cost too much," "health plan problem" - were reported for both preventive and specialty care. Top barriers to physical, occupational, and speech therapy included "health plan problems" and "lack of resources at school" for both groups and "cost too much" for the high complexity group.

Table 2.6. Top three barriers to preventive care, specialty care, and therapies reported by high and low/moderate complexity Children with Special Health Care Needs.

| | High complexity | | Low/Moderate Complexity | |
|---|---|---|---|---|
| *Routine Preventive Care* | | | | |
| Top Barrier | **not convenient times** | 28% | no insurance | 34% |
| Second Barrier | cost too much | 21% | cost too much | 30% |
| Third Barrier | **doctor didn't know how to treat** | 17% | health plan problem | 16% |
| *Specialty Care* | | | | |
| Top Barrier | cost too much | 30% | cost too much | 20% |
| Second Barrier | **not available in area/ transportation** | 24% | health plan problem | 17% |
| Third Barrier | health plan problem | 20% | no insurance | 17% |
| *Physical, Occupational, or Speech Therapy* | | | | |
| Top Barrier | lack of resources at school | 23% | health plan problem | 23% |
| Second Barrier | health plan problem | 20% | lack of resources at school | 21% |
| Third Barrier | **cost too much** | 17% | treatment is ongoing | 17% |

Note: **Bold** denotes barrier is only in the top 3 among high complexity CSHCN

## Discussion

*Summary of Results.* A factor analysis of seven variables confirmed that these variables measure one latent construct of complexity of special health care needs and two variables, number of qualifying health consequences from the CSHCN Screener and severity of functioning limitations, explain 74% of the variance in the latent construct of complexity. These results answer Research Question 1 in the affirmative; it is possible to identify the population of high complexity children with special health care needs using a parsimonious, valid set of variables that represent a single latent construct of highly complex health care needs. To address Research Question 2 – do children with highly complex health care needs represent a unique group of children with special health care needs? – this two-variable measure of complexity was applied to the 2005 NS-CSHCN to identify almost 1 in 10 CSHCN as high complexity (8.8% of CSHCN). This figure extrapolates to more than 1 in every 100 U.S. children, or 1.3% of U.S. kids, (based on 2006 U.S. Census Bureau data). Comparing the demographics and diagnoses of high complexity CSHCN to low/moderate complexity CSHCN, high complexity CSHCN were significantly more likely to be poor, male, and lack adequate insurance. The most striking differences in diagnosis rates were for autism, mental retardation, and cerebral palsy, with high complexity children being highly more likely to be diagnosed with these conditions. High complexity CSHCN were significantly more likely to report a need for services, particularly therapeutic services (94.5% versus 34.9%). Among those who reported a need, high complexity children were significantly more likely to report unmet needs (27.4% versus 9.0%). In a multivariate model, complexity was more strongly

associated with unmet needs than inadequate insurance or poverty. When asked about barriers to obtaining needed preventive and specialty care the low to moderate complexity population reported financial barriers related to inadequate insurance and cost while the high complexity population reported logistical and provider barriers.

*Interpretation of Results.* Prior to this analysis there was a lack of a consistent measure to operationalize the construct of complexity of medical needs within the population of CSHCN. Fourteen previous studies attempting to stratify CSHCN by complexity of health care needs, using 14 unique operationalizations of complexity and focusing on different outcome variables, found that the complexity variables were associated with an increased likelihood of negative outcomes (Antonelli & Antonelli, 2004; Benedict, 2008; Bramlett et al., 2008; Dusing et al., 2004; Fulda et al., 2009; Ganz & Tendulkar, 2006; Inkelas et al., 2007; Kuhlthau et al., 2005; Mayer et al., 2004; Mulvihill et al., 2005; Nageswaran et al., 2008; Nageswaran et al., 2008; Oswald et al., 2007; van Dyck et al., 2004; Warfield & Gulley, 2006). However, it was an open question as to whether these variables measured one latent construct of complexity of health needs, or if these variables identified two separate groups—children with severe health status and children with complex service needs—both of which were associated with negative outcomes. This paper addresses this question by conducting a principal axis common factor analysis of seven variables previously used to operationalize complexity. The analyses revealed that these variables do measure a single latent construct and two variables – number of qualifying health consequences from the CSHCN Screener and severity of functioning limitations – explain the majority of the variance in the seven variable factor score.

*Validation of the two variable measure of complexity*. There were significant and important differences in demographics, diagnoses, and health needs and barriers between the high complexity group and the low/moderate complexity group, indicating that the two variable complexity measure identified a unique group of high complexity children. In addition, the steps taken to validate the complexity measure revealed that this two-variable measure was a good proxy for the latent variable of complexity of health needs. The complexity measure was associated with three criterion variables – unmet need for services, family financial problems related to the child's condition, and inadequate insurance coverage – in the same direction and magnitude as the full model factor score. These three variables have been found in previous research to be significantly associated with the variables contained in the full model factor score ((Huang et al., 2005; Mayer et al., 2004; Nageswaran et al., 2008; van Dyck et al., 2004); (Kuhlthau et al., 2005; Mulvihill et al., 2005). Additional evidence of the validity of the complexity measure is that children in the high complexity subgroup were significantly more likely to report unstable health care needs, more co morbidities, school absences due to illness, more types of services needed, and frequent ER visits; these are the five variables included in the factor analysis but not in the final two-variable complexity measure. This is similar to findings in the adult population where most people who receive the label of "high complexity" report multiple chronic conditions, frequent hospitalizations, and high service utilization (Bodenheimer & Berry-Millet, 2009).

While this is the first study whose main aim was to identify the high complexity subgroup of CSHCN, the finding that 9% of CSHCN were high complexity is consistent with previous research into costs among this population. Cross-sectional health

economics research has shown that ten percent of the CSHCN population accounts for more than two-thirds of health care expenditures for CSHCN (P. W. Newacheck et al., 2004) and a longitudinal analysis found that children with poor health status have the greatest odds of persistently falling in that small high-cost group (Shenkman et al., 2007). The two variable measure of complexity includes screener count and functioning limitations, both of which are associated with poor health status and increased service utilization (Bramlett et al., 2008; Warfield & Gulley, 2006). It is therefore likely that the complexity measure identifies this high cost group.

The next step in the development of this measure is to conduct further validity studies, including exploring the sensitivity and specificity of this measure. This task is more difficult than for other similar measures, e.g. mental health screening tools, because there is no preexisting accepted definition of the construct. One possible study design in the providers office is to use existing medical records to select a high complexity sample from a single pediatric clinic, or a series of pediatric clinics within a health system and compare this sample to the professional qualitative assessments of a team of doctors. Or, also in the clinic setting to expand the definition of complexity to include three or four of the variables used in the factor analysis and compare that larger sample to the two variable measure proposed in this study. Both of these study designs would provide more information on the sensitivity and specificity of this measure. It is also important to note the dynamic nature of this population. The complexity measure is a point-in-time snap shot of the high complexity population. The complexity of a child with special health care needs changes over time as the needs. Future studies should consider conducting re-evaluations of the special needs population in the study, either at the clinic or secondary

data analysis level, in order to ensure to determine how often children cycle in and out of the high complexity population. These types of investigations should be performed before this measure is employed in a practice setting where complete identification of the population is critical.

The two-variable measure does capture the vast majority of the variation in the construct of complexity and is therefore an important tool for research where the goal is to identify a representative sample of high complexity children on which to analyze research and policy questions. The two variables included in this measure – count of health consequences from the CSHCN screener and severity of functioning limitations – are available in the 2001 and 2005 National Survey of Children with Special Health Care Needs. This is the most prominent, nationally representative survey of CSHCN and is the main source of secondary data analysis on CSHCN in the health services literature. Future primary data collection efforts should include these two variables and if there is a financial or logistical limit to the number of questions included these two variables can be prioritized over the other health status and severity variables typically included because this study's factor analysis revealed that the two variable measure captures the majority of the variation in these other variables.

*Demographic profile of the high complexity population*. The results presented above provide support for the main thesis of this paper - children on the complex end of the CSHCN continuum have needs that differ markedly from the broader group and as such should be the focus of independent studies and policy discussions. The first way in which high complexity CSHCN differ is their diagnostic profile. In the high complexity group three conditions had a prevalence over 50% and were significantly more likely

among this group – Attention Deficit Disorder, Mental retardation, and Mental health problems – while one condition, Asthma, was highly prevalent only among the low to moderate complexity group. Another statistic important to note is that almost all children with autism, cerebral palsy, and mental retardation fall into the high complexity group. The U.S. Centers for Disease Control and Prevention (C.D.C.) considers these conditions Developmental Disabilities and they are the focus of research and policy initiatives due to the significant quality of life limitations that accompany these conditions (National Center on Birth Defects and Developmental Disabilities, October 29, 2004). It is therefore not surprising that children with these conditions are predominate in the high complexity group.

This study is the first to explore the diagnostic profile of CSHCN by level of complexity and it appears that high complexity CSHCN are diagnosed with multiple serious developmental disabilities and mental disorders at a much higher rate than low/moderate complexity CSHCN, among which only asthma and allergies are prominent. This diagnostic importation has important implications for health policy related to high complexity children. When policy makers consider the typical child with highly complexity health care needs they may think of disorders more traditionally considered to be in the medical realm such as blood problems, heart problems, muscular dystrophy and epilepsy. While these disorders are significantly more likely in the high complexity population they are low prevalence disorders; most high complexity children have multiple developmental, behavioral, and/or mental health problems. These children have needs for health and supportive services that are more likely to cut across traditional

specialist boundaries and require coordination between the mental health and medical fields.

*Unmet need and barriers to care.* High complexity CSHCN also differ significantly in the types of barriers to care they face and the level of unmet need parents report. Previous studies have found that the level of unmet need for health care among CSHCN is relatively modest; using the 2001 version of the NS-CSHCN Bramlett et al. (2008) found that 10% of all CSHCN reported any unmet need for a variety of direct medical and supportive services. However, there is a difference in unmet need by complexity. Two recent studies using this same dataset reported that 33% (van Dyck et al., 2004) and 34% (Nageswaran et al., 2008) of CSHCN with severe functioning limitations reported any unmet needs. The present study, using the same measure of unmet need, found that 9.0% of low to moderate complexity CSHCN and 27.4% of high complexity CSHCN reported any unmet need. In the previous studies severe functioning limitations served as a one-variable proxy for complexity, the slightly lower level of unmet need among high complexity CSHCN reported in the present study could be the result of using a more restrictive two-variable measure of complexity, or changes in unmet need between the 2001 and 2005 surveys.

Few previous studies have explored unmet need by types of services. This study found the highest levels of unmet need for all CSHCN were for therapeutic and supportive services, with high complexity CSHCN reporting a significantly higher unmet need for both. The most striking difference was for supportive services, high complexity CSHCN were four times more likely to report an unmet need for supportive services. A previous study of children with disability from the 1994 National Health Interview

Survey – Disability Supplement reported unmet need for therapeutic and supportive services. 15% of children with functioning limitations reported unmet need for therapeutic services and 11% reported unmet need for supportive services (Benedict, 2006). These statistics are lower than the 21.8% and 15.5%, respectively, found in this study because the high complexity group includes only those with severe functioning limitations and the lower figures include children with any functioning limitation. This is further support for the proposition that the prevalence of unmet needs increases with increasing complexity of health care needs.

When asked about barriers to obtaining needed preventive and specialty care the low to moderate complexity population predominantly reported financial barriers related to inadequate insurance and cost. The high complexity population reported similar insurance barriers but also reported logistical and provider barriers not frequently reported by the low to moderate complexity group: not available in the area/transportation, doctor didn't know how to treat, not convenient times. An analysis of the 2001 version of the NS-CSHCN assessed the top barriers to care among children who reported delayed or foregone care (Huang et al., 2005). The most frequently reported barriers were financial and only a small percentage reported the logistical and provider barriers that were found to be top barriers to care among the high complexity subgroup of CSHCN. It appears that high complexity CSHCN report unique barriers to care that are not identified when results are not broken down by complexity of health care needs. These logistical and provider factors – geographic access, doctor knowledge, inconvenient times – can be conceptualized as individual level or provider level barriers, and the policy solutions will differ based on this conceptualization, but these barriers are

very different from insurance barriers at the health systems level. When results are not reported separately for high complexity CSHCN the opportunity is missed to identify these unique barriers and to assess their association with the disproportionately high level of unmet need among high complexity CSHCN.

There are important policy implications of utilizing the "high complexity" label to define this group instead of the current system which already distinguishes children based on diagnoses. Diagnoses groups are the focus of biomedical research and are therefore important labels in health services at the individual patient and clinic level in terms of prognosis and treatment goals. However, diagnoses groups include children of varying severity and level of service need and are not as useful when considering health services policy questions related to unmet needs for care and care coordination among multiple providers and services. For example, this study found that three disorders, attention deficit disorder, mental retardation, and mental health problems, have a prevalence of over 50% in the high complexity group. So, policy solutions could involve strengthening the parts of the health system that address these disorders specifically. However, the majority of high complexity CSHCN have multiple co morbidities and report unique barriers and unmet needs that cross the barriers of particular specialties and diagnoses. Identifying children based on the two variable measure of complexity developed in this paper allows researchers and policy makers to identify children with similar needs for services and potential barriers to care across diagnosis groups. This approach will reach a larger population of CSHCN than focusing on single conditions. It is important to note, as mentioned above, that the high complexity population is dynamic and employing the two-variable measure of complexity will identify high complexity CSHCN for the

purposes of research or within a practice setting at one point in time and the population under study will need to be re-evaluated for movement in and out of the high complexity group. The future validity studies discussed in the previous section will serve to inform the frequency with which the population will need to be reevaluated.

*Limitations.* One limitation of this study is the inability of the complexity measure to perfectly capture the latent variable of complexity. 75% of the variance in the full seven variable model score is explained by the two variable measure of complexity. It was not possible to find a combination of variables among the seven previously used to measure complexity that explains a higher amount of variance while maintaining the replicability and parsimony of the measure. It is possible that there are CSHCN which doctors' would consider as having complex health needs who do not score a 4 or 5 on the CSHCN Screener or don't have severe functioning limitations and would therefore not be categorized as high complexity by the complexity measure comprised of these two variables. For example, 4.5% of low to moderate complexity children report that their child's health care needs are unstable. The two variable measure of complexity of service needs would miss these children who may still have complex needs based on one or more of the other five variables used in the factor analysis. In future research in a medical practice setting if complete identification within a patient population is judged to be more important than parsimony, the complexity measure could be expanded to include one or more of the other variables given that the addition of any of them to the two variable measure slightly increased the variability explained by the full model. However, the majority of the children with complex health care needs are captured with the two-variable measure.

These analyses were conducted using cross-sectional data, therefore; while this research identifies factors associated with unmet needs for care, it is not possible to determine the causal direction of the relationship. Despite this fact, this is a crucial area of study because of the potential for barriers identified in this analysis to serve as possible points of effective intervention. In addition, the data for these analyses comes from sample surveys, subject to various forms of non-random error, such as non-response bias. It is possible that families with the most complex children were least likely to respond due to competing demands on their time, and could therefore be underrepresented in the study population. This would lead to an underreporting of the strength of the association between unmet needs and complexity of health needs – a main association of interest.

In addition, it should be noted that reports of unmet need for medical and supportive services are based on parents' experiences and perceptions. This method of measuring unmet need is subject to recognition and recall bias (P. W. Newacheck, Hughes, Hung, Wong, & Stoddard, 2000). In order to report an unmet need a parent must recognize that his/her child has a need that was not filled and the parent must recall the specific situation in which care was needed but not received within the past year, for each of the 15 types of services quarried in the 2005 NS-CSHCN. Errors of recognition or recall could lead to underreporting of unmet needs. It is possible that the problems of recognition and recall bias are not as prominent among the population of children with complex needs because, due to the nature of their children's service needs, caretakers are frequent, and often very savvy, health care consumers. Additionally, measuring unmet need from the parent's perspective allows for a consumer driven understanding of the process of care for families of children with complex special health care needs.

*Conclusion.* This paper makes a significant contribution to research methodology by developing and validating a parsimonious two-variable measure of complexity that will allow for consistent identification of the high complexity subgroup of CSHCN. Applying this measure to the 2005 NS-CSHCN provides support for the main thesis of this paper - children on the complex end of the CSHCN continuum have needs that differ markedly from the broader group. Specifically, high complexity CSHCN present a different diagnostic profile and report an alarmingly high level of parent-reported unmet need when compared to low to moderate complexity CSHCN. Families with high complexity children also report unique barriers to care. More than 1 in 100 U.S. children, or 1.3% of U.S. kids, fall into this vulnerable group (based on 2006 U.S. Census Bureau data).

Given these facts, children with high complexity special health care needs should be the focus of independent studies and policy discussions. Further validation studies are needed to explore the sensitivity and specificity of this measure in addition to its test/re-test reliability. Given the priority of parsimony and representativeness over complex identification in secondary data analysis, future studies utilizing current or future versions of the NS-CSHCN should operationalize complexity based on the measure identified in this study and future primary data collection efforts should prioritize the inclusion of this two-variable measure over other typically included health status and severity variables because this measure captures the majority of the variation in these other variables.

# Chapter 3. Care coordination among children with complex special health care needs

Leading child health policy advocates, including the American Academy of Pediatrics, propose care coordination programs as a solution for reducing barriers to care and unmet need among children with special health care needs (CSHCN) (Council on Children With Disabilities, 2005; Lipkin, Alexander, Cartwright, & Desch, 2005; McAllister, Presler, & Cooley, 2007). Coordinated care is defined as linking patients and families to services and resources across many subsystems of the health and human services field (Gupta, O'Connor, & Quezada-Gomez, 2004). This linkage has been described as a process of assessment, planning, implementation, evaluation, monitoring, support, and advocacy that is facilitated by a designated care coordinator (McAllister et al., 2007). Despite the current policy focus on care coordination, the type and level of assistance that a child with special health care needs receives varies across health systems and families. Coordinated care programs are implemented within primary care providers' offices, specialty clinics, specialty-primary care partnerships, health insurance companies, and social services offices (Antonelli, Stille, & Antonelli, 2008; Gordon et al., 2007; Liptak, Burns, Davidson, & McAnarney, 1998; Stille & Antonelli, 2004).

According to the 2001 National Survey of CSHCN, only 40% of CSHCN who reported needing care coordination received any assistance (Strickland et al., 2004). Barriers to receiving needed care coordination have been identified at multiple levels of the health services system. At the individual patient level minority race, poverty,

uninsurance, and complexity of health needs have been found to be associated with a lack of access to care coordination (Mulvihill et al., 2007; Strickland et al., 2004). At the provider level physicians have reported a lack of time and staff to perform coordination activities and a lack of knowledge and information about care coordination programs (Gupta et al., 2004; Lipkin et al., 2005). The system level barrier cited most frequently in the literature is a lack of insurance reimbursement for care coordination activities (Lipkin et al., 2005; Turchi, Gatto, & Antonelli, 2007). Research into the cost of unreimbursed care coordination programs has shown that the cost is appreciable, but not prohibitive, particularly if the program is funded at the system level where savings from decreased emergency department visits and hospitalizations can be diverted to the program (Antonelli & Antonelli, 2004; Antonelli et al., 2008; Berman et al., 2005).

The science of evaluating coordinated care programs is still in its infancy, particularly for special populations such as CSHCN (McDonald et al., June 2007), but the evaluations that have been conducted reveal positive outcomes for CSHCN and their families, such as improved health, decreased disease burden, and increased parent satisfaction (Gordon et al., 2007; Homer et al., 2008; Liptak et al., 1998; Palfrey et al., 2004; Sutton, Stanley, Babl, & Phillips, 2008; Wood et al., 2009). In addition, there is evidence that the children most severely affected by their conditions receive the greatest benefits (Palfrey et al., 2004; Wood et al., 2009). Based on this evidence coordinated care has been proposed as a policy solution to address the negative health care experiences and high expenditures among the subpopulation of high complexity CSHCN (McAllister et al., 2007; Shenkman et al., 2007). However, there has been no prior

research into where the majority of children with special health care needs receive their care coordination assistance and how many different locations these families rely on.

Three research questions were designed to address these gaps in the literature: (1) what percentage of children with complex special health care needs receive adequate care coordination assistance and who provides this assistance? A description of the current level of care coordination for CSHCN is a necessary first step toward assessing the state of care coordination services in the U.S; (2) what are the sociodemographic and health status correlates of reporting an unmet need for care coordination? Elucidating the factors that are associated with unmet need for care coordination assistance may reveal potential sites for intervention to improve access to care coordination; (3) what is the strength of the association between receipt of care coordination and parent reported unmet need? Specifically, I test the hypothesis that receiving coordinated health care is associated with reductions in unmet needs for medical, therapeutic, and supportive services within the population of children with complex health care needs. Through the investigation of these three research questions this paper presents a profile of care coordination services for children with complex health care needs and explores coordination as a policy solution to reduce unmet needs for care.

## Research Design and Methods

*Data Source.* The data source for this paper was the 2005 National Survey of Children with Special Health Care Needs (2005 NS-CSHCN), sponsored and funded by the U.S. Maternal and Child Health Bureau and fielded in 2005 to collect a nationally representative sample of CSHCN (Blumberg et al., 2008). Please refer to Blumberg et al. (2008) for more extensive information on the design and operation of the 2005 NS-CSHCN. The survey contains data on 40,723 CSHCN. For this analysis, responses were

weighted to represent the national population of CSHCN using the Taylor-series-approximation method in Stata 9. (For more details on the sampling weights see Blumberg et al. 2008).

*Measure of Complexity of Health Care Needs.* This measure included two variables, screener count and functioning limitations. "Screener count" - number of qualifying health consequences - was based on responses to the CSHCN Screener which was developed to standardize the identification of CSHCN (Bethell et al., 2002). To qualify as having special health care needs, a child must currently experience one or more of five health consequences attributable to a medical, behavioral, or other health condition that has lasted or is expected to last for at least 12 months. These consequences include whether the child 1) is limited or prevented in any way in his or her ability to do things most children of the same age can do; 2) needs or uses medications prescribed by a doctor (other than vitamins); 3) needs or uses specialized therapies such as physical, occupational, or speech therapy; 4) has above-routine need or use of medical, mental health, or educational services; or 5) needs or receives treatment or counseling for an emotional, behavioral, or developmental problem. The 2005 NS-CSHCN variable "screener count" is a count of the number of qualifying health consequences, 1-5, reported on the CSHCN screener.

Functional limitations was operationalized as a composite measure of the two questions "How often does the child's health condition affect his/her ability to do age-appropriate things: never, sometimes, usually, always?" and when this occurs "How much limitation does the child experience: very little, some, a great deal?" Functioning limitations was divided into 3 categories, severe, some, or no limitation based on the

coding scheme from Nageswaran et al. (2008). If the response to the first question was never, then the child was coded as "no limitations." If the response to the first question was sometimes and the response to the second questions was some or very little, then the child was coded as "some limitation." If the response to the first question was usually or always or the response to the second question was a great deal, then the child was coded as having "severe limitations".

Complexity was coded as 1 if the respondent reported 4 or 5 qualifying health consequences on the CSHCN screener *and* reported severe functioning limitations. Based on this operationalization, 3,586 children (8.8%) in the dataset fell into the high complexity category (117 respondents, 0.29%, are coded as missing due to missing data for at least one of the two variables). See Hefner (2010, dissertation Chapter 2) for further details on the development and validation of this measure.

*Diagnoses* The child's medical diagnoses were based on parent-report. Respondents were asked "To the best of your knowledge, does the child currently have any of the following: asthma; attention deficit disorder (ADD) or attention deficit hyperactive disorder (ADHD); autism or autism spectrum disorder (ASD); down syndrome; mental retardation or developmental delay; depression, anxiety, an eating disorder, or other emotional problems; diabetes; heart problems; blood problems; cystic fibrosis; cerebral palsy; muscular dystrophy; epilepsy or other seizure disorder; migraine or frequent headaches; arthritis or other joint problems; allergies. For the purpose of this study each diagnosis is a binary variable coded as 1 for each condition the parent reported. A previous analysis of diagnosis rates by complexity using the 2005 NS-CSHCN found that high complexity CSHCN are significantly more likely to report a

diagnosis of autism, down syndrome, mental retardation and cerebral palsy (Hefner 2010, dissertation Chapter 2), therefore, this paper will explore the association between these conditions and unmet needs for care coordination.

*Demographics.* Respondents provided the child's age, gender and ethnicity/race as well as household income level (coded as percent of the federal poverty level). A child was coded as having a usual source of primary care if the parent reported that there was a place the child goes when he/she needs routine preventive care and the child had a personal doctor or nurse. Health insurance was coded as adequate if the parent reported that the child had public or private insurance at the time of the interview, the child had no gaps in coverage during the year before the interview, insurance usually or always met the child's needs, costs not covered by insurance were usually or always reasonable, and insurance usually or always permitted the child to see needed providers. This measure of "adequate insurance" has been found to be inversely associated with unmet needs and negative outcomes in the CSHCN population (Oswald et al., 2007).

*Care Coordination.* In the 2005 NS-CSHCN, the coordinated care module was only asked of respondents who had the potential to need care coordination services, i.e. in the past 12 months their child needed more than one type of service or saw more than one specialty doctor. Children who did not use multiple doctors or services were excluded from the denominator of the care coordination variables. Within the care coordination module respondents could report that they had no need for "extra help arranging or coordinating their child's care among these different health care providers or services." Responding affirmatively to this question also resulted in exclusion from the denominator of the care coordination variables. Therefore, in the following analysis the population of

interest was those families who used multiple services or doctors *and* reported a need for care coordination.

The main care coordination variable used in this analysis was a Maternal and Child Health Bureau (MCHB) outcome indicator, "The family receives effective care coordination services" (Child and Adolescent Health Measurement Initiative (CAHMI), 2007). This was a binary variable coded as 1 if the respondent reported receiving all three components of care coordination: (1) very satisfied with the communication among the child's doctors and other health care providers; (2) very satisfied with the child's doctors' communication with his/her school, early intervention program, child care providers, vocational education or rehabilitation program; and (3) the family usually or always got as much help as they wanted with arranging or coordinating the child's care. Another important variable of interest was who provides care coordination to this population. In the 2005 NS-CSHCN respondents who reported receiving care coordination assistance were asked to check all that apply from a list of 10 possible care coordination providers, including family members, various health care providers, and employees at social services agencies.

*Unmet Need.* The 2005 NS-CSHCN asked parents if the child had a need in the past 12 months for 15 health and supportive services. For each reported need the parent was asked, "Did the child receive all the (fill in the service) care that he/she needed?" For the purposes of this study a child is coded as having an unmet need for care if the parent reported "No" to this question. The main dependent variable was a bivariate measure of any unmet needs coded as 1 if the parent reported 1 or more unmet needs and 0 if no unmet needs were reported. Additional dependent variables were four categories of

health care services: preventive care, specialty care, therapeutic services (occupational, physical, and speech therapy; mental health; or substance abuse services), and supportive services (specialized equipment, transportation, home health, or respite care). Therapeutic and supportive services was defined as proposed by Benedict (2008). These binary variables were coded as 1 if the parent reported an unmet need within these four categories.

*Analysis.* The analysis consisted of descriptive analyses of the sociodemographic variables by the care coordination variables and bivariate tests for a difference in means to address Research Question 1. To examine independent associations between these individual level variables and unmet need for care coordination, Research Question 2, I conducted a multivariate logistic regression with the dichotomous measure of care coordination as the dependent variable. Next, to test the hypothesis that receiving coordinated health care is associated with reductions in unmet needs for services, Research Question 3, I conducted five multivariate logistic regressions with care coordination as the main independent variable of interest and the five unmet need for services variables as the dependent variables: any unmet need and unmet need for four categories of services. Control variables included insurance and poverty – the two variables associated with complexity in bivariate tests and also found to be associated with unmet needs for care (Mayer et al., 2004; van Dyck et al., 2004) as well as age, race, and gender. All analyses were conducted using the complex survey design functions of Stata 9.2.

## Results

In the 2005 NS-CSHCN there were 40,721 respondents; 3,586 respondents were categorized as high complexity representing 8.9% of U.S. CSHCN. The sample analyzed

in this paper was CSHCN, both high and low/moderate complexity (defined as the remaining CSHCN sample) who used two or more types of services and reported needing assistance with care coordination. 95.8% of high complexity CSHCN fit this definition, resulting in a sample size of 3,436 for the high complexity group. 70.8% (N=26,313) of low to moderate complexity CSHCN fit this definition.

Table 3.1 presents the level of care coordination among CSHCN by complexity and diagnosis. Analyzing the full CSHCN sample from the 2005 NS-CHSCH, 35.6 % of high complexity CSHCN received effective care coordination services versus 62.1% of low to moderate complexity CSHCN. The effective care coordination measure is coded affirmatively if the child received all of the three care coordination variables: 47.0% of families with high complexity CSHCN were very satisfied with communication among the child's doctors, 43.0% were very satisfied with communication among the child's doctors and other support programs and 47.1% reported usually or always receiving help coordinating care when they need assistance. These percentages were significantly lower than for low to moderate complexity CSHCN (66.3%, 55.4%, and 70.7% respectively, $P < 0.000$).

Not receiving effective care coordination was significantly associated with reporting a diagnosis of all four disorders at $P < 0.05$. The largest differential in receiving effective care coordination by diagnosis was for autism, 36.9% of those with autism received effective care coordination versus 61.0% of those without an autism diagnosis. That is a 24 percentage point reduction in access to effective care coordination by diagnosis. 43.4% of CSHCN with down syndrome report effective care coordination assistance versus 59.4% of those who don't have down syndrome. Among children with

a diagnosis of mental retardation or developmental delay 42.6% received effective care coordination versus 61.9% without mental retardation. 47.8% of those with cerebral palsy reported effective care coordination compared to 59.5% of those without a cerebral palsy diagnosis.

Table 3.1: Level of Care coordination among Children with Special Health Care Needs by complexity and diagnosis.

**Measures of Care Coordination**

| **Health Status** | Effective Coordination, composite of 3 variables | | Very Satisfied communication among child's doctors | | Very satisfied communication among child's doctors and other programs | | Family usually/ always receives help coordinating child's care | |
|---|---|---|---|---|---|---|---|---|
| *Complexity* | | | | | | | | |
| High complexity CSHCN, N=3,436 | 35.6% | * | 47.0% | * | 43.0% | * | 47.1% | * |
| Low/Moderate Complexity, N=26,313 | 62.1% | | 66.3% | | 54.5% | | 70.7% | |
| *Autism or Autism Spectrum Disorder* | | | | | | | | |
| Diagnosed with Autism | 36.9% | * | 46.1% | * | 43.0% | * | 45.0% | * |
| No diagnosis of Autism | 61.0% | | 65.5% | | 53.5% | | 69.8% | |
| *Down Syndrome* | | | | | | | | |
| Diagnosed with Down Syndrome | 43.4% | * | 55.8% | | 43.7% | | 54.3% | * |
| No diagnosis of Down Syndrome | 59.4% | | 64.0% | | 52.2% | | 67.6% | |
| *Mental Retardation/Developmental Delay* | | | | | | | | |
| Diagnosed with Mental Retardation | 42.6% | * | 54.2% | * | 45.9% | * | 56.1% | * |
| No Diagnosis of Mental Retardation | 61.9% | | 65.8% | | 53.9% | | 69.8% | |
| *Cerebral Palsy* | | | | | | | | |
| Diagnosed with Cerebral Palsy | 47.8% | * | 61.6% | | 55.2% | | 63.5% | |
| No Diagnosis of Cerebral Palsy | 59.5% | | 64.0% | | 52.0% | | 67.5% | |

Notes: Percentages weighted to reflect the national population of CSHCN ; "Effective Coordination" is coded for if all three other coordination variables are "Yes";asterisk indicates that levels of care coordination are significantly different across values of the independent variables ($p < 0.05$).

Given that complexity is a significant predictor of unmet need for care coordination, Table 3.2 explores potential correlates of unmet need among the high complexity population. Child age, ethnicity, gender, household income and reporting a usual source of primary care were not significantly associated with reporting an unmet need for care coordination (Table 3.2). Among this high complexity group the only sociodemographic characteristic significantly associated with receiving effective care coordination assistance was reporting adequate insurance coverage ($P < 0.000$). 44.3% of those with adequate insurance coverage received effective care coordination versus 26.5% of those with inadequate coverage. Among the high complexity population, a multivariate logistic regression (results not in table) of the sociodemographic variables from Table 3.2, the four diagnostic categories, and inadequate insurance coverage on unmet need for care coordination revealed that diagnostic categories and sociodemographic variables were not significantly associated with care coordination. Controlling for these other variables, among high complexity children the odds of reporting unmet needs for care coordination were 2.30 times greater for families with inadequate insurance (95% CI 1.77-2.99).

Table 3.2: Level of Care coordination among high complexity Children with Special Health Care Needs by sociodemographic characteristics.

| | Measures of Care Coordination | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Sociodemographic Characteristics** | Effective Coordination, composite of 3 variables | | Very Satisfied communication among child's doctors | | Very satisfied communication among child's doctors and other programs | | Family usually/ always receives help coordinating child's care | |
| *Among High Complexity CSHCN (N=3,436)* | | | | | | | | |
| *Child Age* | | | | | | | | |
| 0-5 years old | 38.0% | | 48.4% | | 43.4% | | 53.1% | |
| 6-11 years old | 36.2% | | 47.6% | | 44.8% | | 46.0% | |
| 12-17 years old | 33.7% | | 45.8% | | 40.9% | | 44.5% | |
| *Child Ethnicity* | | | | | | | | |
| White, non-Hispanic | 36.7% | | 48.4% | | 43.0% | | 48.6% | |
| Hispanic | 30.6% | | 41.5% | | 42.1% | | 47.1% | |
| Black/African-American | 37.7% | | 50.3% | | 45.7% | | 48.1% | |
| Multi racial, Other (including Asian) | 30.4% | | 40.6% | | 38.4% | | 31.9% | |
| *Child Gender* | | | | | | | | |
| Male | 35.9% | | 46.8% | | 43.0% | | 46.7% | |
| Female | 35.2% | | 47.5% | | 43.3% | | 48.1% | |
| *Household Income (% FPL)* | | | | | | | | |
| < 100 % | 36.1% | | 50.6% | | 45.9% | | 49.1% | |
| 100-200 % | 32.1% | | 45.5% | | 40.3% | | 45.6% | |
| 200-400 % | 42.1% | | 50.2% | | 47.9% | | 50.7% | |
| > 400 % | 30.9% | | 40.4% | | 35.9% | | 41.3% | |
| *Usual source of primary care* | | | | | | | | |
| Child does not have usual source of care | 37.6% | | 49.8% | | 45.3% | | 51.9% | |
| Child has usual source of care | 35.3% | | 46.7% | | 42.7% | | 46.5% | |
| *Inadequate insurance* | | | | | | | | |
| Child does not have adequate insurance | 26.5% | * | 38.6% | * | 33.9% | * | 35.3% | |
| Child has adequate insurance | 44.3% | | 55.3% | | 52.0% | | 60.0% | |

Notes: Percentages weighted to reflect the national population of CSHCN; "Effective Coordination" is coded for if all three other coordination variables are "Yes";asterisk indicates that levels of care coordination are significantly different across values of the

independent variables ($p < 0.05$).

To examine the association between receiving assistance with care coordination and unmet needs for health and supportive services, Research Question 3, Table 3.3 presents three multivariate logistic regressions conducted on the sample of high complexity CSHCN. Inadequate care coordination was regressed on the unmet need variables, controlling for inadequate insurance, poverty, age, race, and gender and four diagnostic categories – autism, down syndrome, mental retardation and cerebral palsy. Among high complexity CSHCN, the odds of reporting any unmet needs were 3.16 greater for families who reported inadequate care coordination ($P < 0.000$, 95% CI 2.25-4.43). Inadequate care coordination was also independently associated with a significant increase in the likelihood of reporting unmet needs for therapies (OR = 3.01, 95% CI 2.03-4.46) and supportive services (OR = 2.67, 95% CI 1.40-2.09). Inadequate insurance was significantly associated with reporting any unmet needs (OR = 2.64, 95% CI 1.98-3.52) and unmet need for therapeutic services (OR = 2.45, 95% CI 1.78-3.37), but not significantly associated with unmet need for supportive services (OR = 1.53, 95% CI 0.93-2.53). All multivariate associations between the unmet need variables and poverty, age, race and gender were not significant. Among the diagnostic categories, the odds of reporting any unmet needs and unmet need for therapeutic services were 2.31 (95% CI 1.36-3.92) and 2.20 (1.23-3.94) greater, respectively, for those with a diagnosis of down syndrome. The odds of reporting unmet needs for supportive services were 2.05 (95% CI 1.29-3.27) greater for those with autism and 1.84 ( 95% CI 1.06-3.18) greater for those with cerebral palsy.

Table 3.3. Unmet need and inadequate care coordination among children with complex health care needs.

*Multivariate Logistic Regressions*

*D.V. = Unmet needs for health and supportive services*

| | Any unmet needs | | | Therapeutic services | | | Supportive services | | |
|---|---|---|---|---|---|---|---|---|---|
| | Odds Ratio | 95% CI | | Odds Ratio | 95% CI | | Odds Ratio | 95% CI | |
| Inadequate care coordination | **3.16** | (2.25-4.43) | *** | **3.01** | (2.03-4.46) | *** | **2.67** | (1.40-2.09) | ** |
| Inadequate Insurance | **2.64** | (1.98-3.52) | *** | **2.45** | (1.78-3.37) | *** | 1.53 | (0.93-2.53) | |
| Poverty | 1.06 | (0.93-1.19) | | 0.97 | (0.84-1.09) | | 1.08 | (0.85-1.36) | |
| Gender | 0.81 | (0.60-1.19) | | 0.81 | (0.59-1.11) | | 0.63 | (0.38-1.05) | |
| Age | 1.00 | (0.83-1.21) | | 1.02 | (0.83-1.26) | | 0.91 | (0.66-1.24) | |
| Race | 1.09 | (0.93-1.28) | | 1.06 | (0.88-1.26) | | 1.16 | (0.89-1.50) | |
| Autism | 1.26 | (0.95-1.68) | | 1.22 | (0.88-1.68) | | **2.05** | (1.29-3.27) | ** |
| Down Syndrome | **2.31** | (1.36-3.92) | ** | **2.20** | (1.23-3.94) | ** | 1.74 | (0.67-4.49) | |
| Mental Retardation | 0.99 | (0.73-1.35) | | 0.98 | (0.71-1.37) | | 1.43 | (0.76-2.70) | |
| Cerebral Palsy | 1.35 | (0.85-2.15) | | 0.96 | (0.59-1.56) | | **1.84** | (1.06-3.18) | * |

Note: * p<0.05, ** p<0.01, *** p<0.001; Any unmet needs include preventive and specialty care however, the level of unmet need for these services was too small to warrant separate analysis of these variables.

39.0% of families with high complexity children reported that someone helps them arrange or coordinate their children's care. Table 3.4 presents the most frequently reported sources of care coordination among the families who report receiving assistance, presented separately for those who report an unmet need for care coordination assistance and those who receive effective care coordination. The response categories were not mutually exclusive allowing the respondents to report more than one source of assistance. Among families with an unmet need for care coordination 54.4% received assistance from the doctor's office, 21.9% from a case manager, 23.5% from a parent and 9.4% from a social worker. Among families who receive effective care coordination assistance 71.5% received assistance from the doctor's office, 15.2% from a case manager, 11.5% from a parent and 15.3% from a social worker. Based on bivariate chi-square tests of association, significantly more families who received effective care coordination reported receiving assistance from the doctor's office and significantly fewer reported a parent as a source of assistance than families with an unmet need for care coordination ($P<0.05$).

Table 3.4. Most frequently reported sources of care coordination assistance among families with high complexity Children with Special Health Care Needs by receipt of effective care coordination

| | Unmet need for care coordination | Effective care coordination | |
|---|---|---|---|
| Doctor's Office | 54.4% | 71.5% | * |
| Case Manager | 21.9% | 15.2% | |
| Parent | 23.5% | 11.5% | * |
| Social Worker | 9.4% | 15.3% | |
| Therapist | 7.3% | 6.6% | |
| Other Family Member | 5.9% | 6.0% | |
| Friend | 0.9% | 0.7% | |
| Guardian | 2.1% | 3.4% | |
| Nurse | 4.5% | 3.5% | |
| Hospital Discharge Planner | 0.2% | 0.9% | |

Note: Asterisk denotes that percentages are significantly different by unmet need for care coordination at $P<0.05$; Response categories are not mutually exclusive; Percentages are weighted to reflect the national population of CSHCN.

## Discussion

*Receipt of care coordination by complexity of health care needs and specific disorders.* Research Question 1 queries the level of care coordination received by children with complex health care needs. This study found that 36% of high complexity children with special health care needs receive effective care coordination services versus 62% of low to moderate complexity children. That significant difference persists across the three care coordination variables with the largest difference for "family always/usually receives help coordinating care (47.1% versus 70.7%, $P < 0.000$). A previous analysis of diagnosis rates by complexity of health care needs using the 2005 NS-CSHCN found that high complexity children with special health care needs are significantly more likely to report a diagnosis of autism, down syndrome, mental retardation and cerebral palsy (Hefner 2010, dissertation Chapter 2). Therefore, this paper examined the association between these conditions and unmet needs for care coordination. Not receiving effective care coordination was significantly associated with reporting a diagnosis of all four disorders. The largest differential in receiving effective care coordination by diagnosis was for Autism, 36.9% of those with autism received effective care coordination versus 61.0% of those without an autism diagnosis. That is a 24 percentage point reduction in access to effective care coordination by diagnosis.

Despite the fact that compared to the general population of children with special health care needs, children with complex needs have a higher need for care coordination assistance (Antonelli & Antonelli, 2004) and receive the greatest benefits from care coordination programs (Palfrey et al., 2004; Wood et al., 2009), high complexity CSHCN and those with highly complex disorders report reduced access to care coordination. The

fact that these children have a greater need for care coordination would be expected to lead to a higher level of unmet care coordination needs. So while the high level of unmet need is not unexpected, given the benefits of care coordination for these children, it is imperative to search for potential points of intervention to improve access to care coordination for this group. Given this, the next step was to evaluate Research Question 2, what are possible correlates of unmet need for care coordination among the high complexity population, by exploring the variation in access to care coordination within the high complexity subgroup.

*Correlates of unmet need for care coordination among complex CSHCN*. Among the general population of children with special health care needs, minority race, poverty, uninsurance, and complexity of health needs have been found to be associated with a lack of access to care coordination (Mulvihill et al., 2007; Strickland et al., 2004). This study emphasizes past findings that complexity of health care needs is strongly associated with unmet needs for care coordination, and then expands beyond previous studies to examine predictors of unmet care coordination needs among the high complexity population. A multivariate logistic regression of predictors of unmet need for care coordination found that diagnostic categories and sociodemographic variables were not significantly independently associated with care coordination. This finding indicates that specific diagnoses are indicators of complexity in the general population of CSHCN – based on the association of autism, down syndrome, mental retardation and cerebral palsy with unmet needs for care coordination - but once complexity of health care needs is accounted for by examining only the high complexity sample there is not something unique about these diagnoses that is associated with a lack of access to care coordination.

Controlling for these diagnoses and sociodemographic variables, inadequate insurance coverage was the only measured variable associated with care coordination.

This finding highlights the need for future research into what aspects of insurance coverage are associated with increased access to care coordination because many of the families that were coded as having "inadequate insurance coverage" did have insurance in the past year but reported either gaps in coverage or underinsurance problems such as a lack of coverage for needed services or high out of pocket costs. In 2010 "The Patient Protection and Affordable Care Act" became law and when enacted will expand coverage to families who may have gaps in insurance coverage or have trouble getting coverage because of their child's pre-existing condition and therefore may have an impact on the level of unmet need for care coordination among high complexity CSHCN. However, this law does not directly address the other causes of underinsurance, such as out of pocket costs and coverage of specific needed services. Research is needed into which aspects of insurance increase access to care coordination and then changes in health insurance policy can be considered that would have a greater likelihood of improving access.

It is unlikely that inadequate insurance coverage is the only factor associated with access to care coordination among this group. The fact that underinsurance is the only sociodemographic variable that predicts access to care coordination is evidence that other unmeasured variables, possibly at the health services rather than individual level, may be driving the high level of unmet need in this group. Previous studies of physician and system level barriers provide support for this hypothesis. Doctors' report that it is particularly difficult to coordinate care for their most complex patients, who average a

higher number of encounters and necessitate a larger amount of time spent in care coordination activities (Antonelli & Antonelli, 2004; Davidson, Silva, Sofis, Ganz, & Palfrey, 2002). In order to reduce the unmet needs for care coordination faced by children with complex health needs it is critical that future studies explore these provider level barriers.

*Location of care coordination assistance.* Despite the current policy focus on care coordination, the type and level of assistance that a child with special health care needs receives varies across health systems and families. Previous research has described care coordination programs within primary care providers' offices, specialty clinics, specialty-primary care partnerships, health insurance companies, and social services offices (Antonelli et al., 2008; Gordon et al., 2007; Liptak et al., 1998; Stille & Antonelli, 2004). Our results reveal that while children with complex health needs are indeed receiving care coordination assistance at all of these locations, the majority report receiving assistance from their doctor or someone in the doctor's office. Among high complexity children, unmet need for care coordination is associated with location of care coordination. Significantly more families who received effective care coordination reported receiving assistance from the doctor's office and significantly fewer reported a parent as a source of assistance than families with an unmet need for care coordination. The survey questions in the 2005 NS-CSHCN do not differentiate between assistance from a primary care provider or a specialist's office. There is debate in the literature regarding whether care coordination programs are most effective when facilitated by the pediatrician, a specialist clinic, or a primary care/specialty partnership (Alexander et al., 2005; Graham, 2008; McAllister et al., 2007; Sutton et al., 2008). In future versions of

the NS-CSHCN the question wording should be altered to include a choice between pediatrician's office and specialist's office in order to provide for descriptive statistics to inform this current policy debate.

*Unmet Need and Care Coordination.* Coordinated care has been proposed as a policy solution to address the negative health care experiences and high expenditures among the subpopulation of high complexity CSHCN (McAllister et al., 2007; Shenkman et al., 2007). Research Question 3, is there an association between receipt of care coordination and parent reported unmet need, examines this policy solution. In fact, the results presented in this paper find evidence to support this position. Specifically, high complexity CSHCN who do not receive adequate care coordination are three times more likely to report unmet needs for health and related services, controlling for child and family demographics, inadequate insurance, and four disorders prevalent in the high complexity population. Inadequate insurance, Down Syndrome, and Cerebral Palsy were also significantly associated with the unmet need variables. However, in the multivariate model care coordination was a stronger predictor of unmet needs than inadequate insurance or specific diagnoses.

Hefner (2010, dissertation Chapter 2) found that high complexity children with special health care needs report logistical barriers to care not prominently reported by the low/moderate complexity population: clinic not available in the patient's area, transportation problems, and inconvenient clinic times. Coordinated care is defined as linking patients and families to services and resources across many subsystems of the health and human services field (Gupta et al., 2004). Inherent in this definition is the goal of enhancing access to services and resources (McAllister et al., 2007). A

longitudinal evaluation of a coordinated care demonstration project for CSHCN, conducted at six pediatric primary care practices, found that two years after program implementation families reported improvements in accessing care, including getting appointments, referrals, transportation, and respite care (Palfrey et al., 2004). These benefits are the specific logistical barriers to care identified by Hefner's (2010) dissertation research. Another longitudinal study of a similar primary care based coordinated care intervention for CSHCN found that parents reported reduced barriers to services after participating in the program for 18 months, but parents were not questioned about specific barriers (Wood et al., 2009). These studies provide evidence that receiving care coordination assistance ameliorates the logistical barriers reported most frequently by families with high complexity CSHCN, which at least partially explains the striking reduction in unmet need among those who receive adequate care coordination assistance.

*Limitations.* These analyses utilized cross-sectional data, therefore; while this research identifies factors associated with unmet needs for care, it is not possible to determine the causal direction of the relationship. Despite this fact, this is a crucial area of study because of the potential for barriers identified in this analysis to serve as possible points of effective intervention. In addition, the data for these analyses comes from sample surveys, subject to various forms of non-random error, such as non-response bias. It is possible that families with the most complex children were least likely to respond due to competing demands on their time, and could therefore be underrepresented in the study population. This would lead to an underreporting of the strength of the association between coordinated care and complexity of health needs – a main association of interest.

In addition, it should be noted that reports of unmet need for medical and supportive services are based on parents' experiences and perceptions. This method of measuring unmet need is subject to recognition and recall bias (P. W. Newacheck et al., 2000). In order to report an unmet need a parent must recognize that his/her child has a need that was not filled and the parent must recall the specific situation in which care was needed but not received within the past year, for each of the 15 types of services quarried in the 2005 NS-CSHCN. Errors of recognition or recall could lead to underreporting of unmet needs. It is possible that the problems of recognition and recall bias are not as prominent among the population of children with complex needs because, due to the nature of their children's service needs, caretakers are frequent, and often very savvy, health care consumers. Additionally, measuring unmet need from the parent's perspective allows for a consumer driven understanding of the process of care for families of children with complex special health care needs.

*Conclusion.* Children with complex special health care needs are a vulnerable population at risk for barriers to care, unmet needs for health services, and poor health and quality of life outcomes. The results presented in this paper provide support for the hypothesis that receiving adequate assistance with care coordination is associated with reductions in unmet needs for medical, therapeutic, and supportive services within the population of children with complex health care needs. However, only 35.6% of high complexity children with special health care needs receive effective care coordination compared to 62.1% of low to moderate complexity CSHCN. Among a list of patient and family sociodemographic characteristics and four disorders prominent in the high complexity population, inadequate insurance is the only individual level variable that is

independently associated with unmet need for care coordination. This finding, and previous evidence of provider and system level barriers to implementing care coordination programs for children with complex needs, may be an indication that variables at the health services rather than the individual level are important factors in the high level of unmet need for assistance with care coordination among children with complex health care needs. Given the significant impact of care coordination on unmet needs for care among this vulnerable population it is critical that future studies explore provider and system level barriers to care coordination.

# Chapter 4. Children dependent on ventilators and the health services system: unmet needs and coordination of health services.

As a result of improvements in perinatal technology and the treatment of childhood trauma and disease, the number of children dependent on mechanical ventilation is growing (Carnevale, Rehm, Kirk, & McKeever, 2008; Wang & Barnard, 2004). These children rely on medical technology to sustain the basic life function of breathing; and because of this dependence most require continuous nursing care, provided either by a nurse or a trained parental care giver, an ongoing supply of expensive equipment, and frequent intense contact with the health care system. These characteristics make children dependent on ventilators unique among the population of children with complex health care needs (Kirk, 1998; Wang & Barnard, 2004).

Despite this fact, there is a lack of state or nationwide data on the prevalence and characteristics of ventilator-dependent children (Lewarski & Gay, 2007). In response to this gap, researchers in both Utah (Gowans, Keenan, & Bratton, 2007) and Massachusetts (Graham, Fleegler, & Robinson, 2007) have conducted a state-level census of the population dependent on home mechanical ventilation in their respective states. Both of these studies collected basic data on age, gender, diagnostic category, and type of ventilation. While the Utah study did include insurance status and rural versus urban residence, neither study collected enough variables to develop the type of comprehensive demographic and health status profile that is necessary for developing appropriate systems of health service delivery. In addition to its usefulness for program

development, information about the distribution of condition severity, functional ability, and co-morbidities within this population is important for answering questions related to barriers to health services.

Children dependent on ventilators are a vulnerable population by virtue of their chronic disability and are therefore at greater risk for health disparities and access barriers (Aday, 1994). Despite this fact, and the documented access problems among the broader population of high complexity CSHCN (Benedict, 2008; Dusing et al., 2004; Ganz & Tendulkar, 2006; Inkelas et al., 2007; Inkelas et al., 2007; Kane et al., 2005), there is little known about the experiences of children on ventilators within the health services system. Ventilator-dependent children typically require highly technical medical care across multiple subspecialties and a variety of social services (Lewarski & Gay, 2007). Their complex patterns of utilization and multiple points of entry present a challenge to the coordination of the health care system (Graham, 2008). However, studies of families with technology dependent children have focused on parents' experiences as home caregivers – the social and emotional impact on the family and financial strain – (Fields, Rosenblatt, Pollack, & Kaufman, 1991; Kirk, Glendinning, & Callery, 2005; Wang & Barnard, 2004) or the cost effectiveness of home care compared to hospitalization (Kirk et al., 2005; Ottonello et al., 2007; Sevick & Bradham, 1997), with little consideration of the interaction between these families and the health care system. No published study to date, to my knowledge, has sought to identify the unmet needs and access barriers faced by families' caring for a child on a ventilator or the level of care coordination they receive.

To fill these gaps in the research this study will explore three research questions: (1) what is the demographic and health status profile of ventilator dependent children? This type of detailed information on this vulnerable population is necessary for program development and also to explore correlates of barriers and unmet needs; (2) what unmet needs for medical and therapeutic services do these families report and what access barriers do they face? Despite the risk factors inherent in the nature of these children's disabilities there is a lack of research on this topic; (3) what is the level of unmet need for care coordination assistance within a defined care coordination program and what variables are associated with this unmet need? If there is indeed a high level of unmet need among this population, care coordination assistance may be a way to ameliorate the barriers to care faced by this vulnerable population. A survey was developed in conjunction with clinic administrators at the study site in order to collect data to address these questions.

## Research Design and Methods

This study will present a profile of ventilator dependent children and their families who attend a Pediatric Home Ventilator Clinic at a large Midwestern medical center. This clinic is unique because it has a defined care coordination program with the mission to coordinate care in the continuum from hospital discharge to home in the child's local community. In addition to presenting a demographic, diagnostic, and family status profile of the patient population this study will assess the relationship of these variables to unmet needs for assistance with care coordination and explore the association between care coordination and unmet needs for health and supportive services.

*Description of the study site.* This home ventilator program is unique because it provides the patients and their families with a defined care coordination program. At a weekly clinic the patient is seen by a multidisciplinary team of providers including a pulmonary doctor, a physical medicine and rehabilitation doctor, a respiratory therapist, a dietitian, and a social worker. At the conclusion of each clinic session there is a team meeting during which each patient seen that day is discussed and consensus is reached on future treatment and social service needs. The clinic also includes a R.N. and a N.P. who conduct daily care coordination activities with the multiple health and social service agencies that care for the clinic patients. These care coordination activities include both phone consultations with patients' families and providers and in person visits to the patient's local community.

*Data Collection.* A survey was fielded at a Pediatric Home Ventilator Clinic at a large Midwestern medical center. The study sample was a convenience sample of parents whose children attended home ventilator clinic at the study site during the specified "Home Ventilator Clinic" days. The inclusion criteria for the study were: 1) parent or guardian of a child who has at some point relied on home mechanical ventilation (either invasive or non-invasive); 2) the child is a patient with a clinic appointment during the study period. Data collection at the site occurred over a period of nine months, from March 2009 until December 2009. The survey was anonymous and posed no more than minimal risk to the participants, therefore, the local IRB granted the study a waiver of signed consent. Each participant received a prepaid monetary incentive of five dollars, which has been shown to significantly increase response rates among a variety of populations, including Medicaid enrollees (Beebe, Davern, McAlpine, Call, &

Rockwood, 2005; Church, 1993; Saunders, Jobber, & Mitchell, 2006). The protocol at the study site was as follows: The clinic R.N. attended each weekly clinic session and was responsible for the implementation of the in-clinic survey protocol. She identified the parent or guardian of each clinic patient; approached the parent/guardian after check-in; described the study via the recruitment script and requested participation; provided the participant with a clipboard, pen and an envelope that contained the one-page consent form, the incentive, and the survey instrument; and informed the participant they had the entire clinic appointment to complete the survey. At the end of the participant's clinic visit he/she was instructed to put the survey in the provided privacy envelope and place it in the collection box at the check-in desk or give it to any clinic staff member. If the respondent did not have time to complete the survey he/she was given a postage paid envelope addressed to the PI to mail at his/her convenience.

*Variables and Measurement.* Respondents provided the child's age, gender and ethnicity/race based on questions from the 2005 NS-CSHCN (Blumberg et al., 2008). Family income was operationalized as one question assessing the family's current financial situation – possible responses were "It's a financial struggle," "It's tight but we're doing fine," or "Finances aren't really a problem" (Eisenberg, Golberstein, & Gollust, 2007). Family education was measured as the highest level of school anyone in the household has completed: "high school degree or less", "some college", or "college graduate". Caregiver mental health was measured using the two item Patient Health Questionnaire (PHQ-2); a validated measure of depression severity (Kroenke, Spitzer, & Williams, 2003). The PHQ-2 asks about the frequency of depressed mood and anhedonia over the past 2 weeks, scoring each as 0 ("not at all") to 3 ("nearly every day").

Following the standard algorithm for this instrument respondents with a score of 3 or greater were coded as screening positive for major depression. Daily parent contribution to caregiving was operationalized as the number of daily hours of family provided direct patient care, not including in-home professional nursing.

Functional limitations was operationalized as a composite measure of the two questions "How often does the child's health condition affect his/her ability to do age-appropriate things: never, sometimes, usually, always?" and when this occurs "How much limitation does the child experience: very little, some, a great deal?" Functioning limitations is divided into 3 categories, severe, some, or no limitation based on the coding scheme from Nageswaran et al. (2008). If the response to the first question was never, then the child was coded as "no limitations." If the response to the first question was sometimes and the response to the second questions was some or very little, then the child was coded as "some limitation." If the response to the first question was usually or always or the response to the second question was a great deal, then the child was coded as having "severe limitations".

Receipt of assistance with care coordination was assessed based on two questions from the 2005 NS-CHSCN (Blumberg et al., 2008). "Does anyone help you arrange or coordinate your child's care among the different doctors or services that he/she uses?" and "During the past 12 months have you felt you could have used extra help arranging or coordinating your child's care?" Unmet need for care coordination is a binary variable coded as 1 if the family reported they don't receive help but reported a need for help, or the family receives help but reported needing extra help arranging or coordinating the child's care.

Unmet needs for services were assessed based on the question, "During the past 12 months did your child receive all the 'one of five types of services' that he/she needed?" This question was asked for preventive care, specialty care, therapy, home health care, and special medical equipment. For the purposes of this study a child is coded as having an unmet need for care if the parent reported "No" to this question. Barriers to care were assessed based on the question "Please share the reasons you had trouble trying to get 'the service' for your child, check all that apply," for each of the five types of services: preventive care, specialty care, therapies, home health care, special medical equipment. This prompt was followed by a list barriers unique to each service type and developed based on write-in answers to this question during pre-testing and discussion with clinic administrators. An "other reasons, please list" category was included after each list of barriers.

*Analysis.* To address Research Questions 1 and 2 a descriptive analysis of the full home ventilator sample was conducted. Means for variables including patient demographics, family socioeconomic status, patient health status, unmet needs for care, and barriers to care were calculated. Research Question 3 was analyzed by reporting the percentage of the population that received care coordination, the level of unmet need for care coordination, and the top five locations of this assistance. A series of bivariate t-tests of association between levels of the patient characteristic variables and unmet need for care coordination were conducted to determine if any patient level factors were associated with unmet need for care coordination. A multivariate logistic regression including any significant patient level variables was conducted to determine independent associations with unmet need for care coordination. The association between unmet need

for care coordination and unmet need for services was explored through a series of chi square tests of the association between unmet need for care coordination and three variables: unmet need for therapeutic services, unmet need for home health care, and unmet need for medical equipment. All analyses were conducted using Stata 9.2.

## Results

At the start of the data collection period in March 2009 there were 145 children on the current patient list of the Pediatric Home Ventilator clinic who fit the eligibility criteria (47 patients on the list were excluded because they were not yet on a ventilator, had transferred to another clinic, or were deceased). The study population was a convenience sample of parents whose children attended the weekly Wednesday home ventilator clinic during the nine month data collection. Data collection was concluded in December 2009 because the rate of new survey completions had slowed to a level below the costs of staff time to continue data collection. 124 parents or guardians of clinic patients were given the survey. 122 parents completed the survey during their clinic visit resulting in a response rate of 98% (2 surveys were taken home to complete but were never returned). These 122 responses represent 84% of the eligible patient population. Of the 23 children who did not attend the weekly Wednesday clinic during the data collection period 14 attended an occasional Thursday clinic held at an alternative location and the only difference between these children and those surveyed was that the alternative location was more convenient for them. Nine patients were unaccounted for and it is most likely that these patients attend clinic only yearly, as opposed to the typical six month return visit, and their yearly visits occurred before data collection began in March.

To explore Research Question 1 - what is the demographic and health status profile of ventilator dependent children? - a description of the patient demographics, patient health status, and family socioeconomic status of the survey sample is presented in Table 4.1. Almost half (47.9%) of the study sample was between three and fifteen years old, 21.5% were two years or less and 30.6% were sixteen to thirty years old. More than two-thirds of the patients were White, non-Hispanic (76.7%), 15.8% were Black/African-American, 2.5% were Hispanic, and 5.0% reported more than one of these three racial categories or selected the "other" category. The patient population was split almost evenly between male and female, 54.1% and 45.9% respectively.

The respondents were presented with five response choices to the question: "What is the reason your child requires/required a ventilator, meaning the diagnosis or medical condition? Check all that apply." There was also an "Other, please write in" response choice. 19 respondents wrote in a response and of those 15 could be coded into one of the five response categories by the Director of the clinic, a physician specializing in Pediatric Pulmonology. In order of most frequently reported condition category: 45.1% reported a lung condition, 27.0% reported a neuromuscular condition, 27.0% reported an airway condition, 22.1 % reported a brain condition, 7.4 % reported a spinal cord injury, and 4.1% checked "Other" and the response could not be re-coded. 94.3% of the children in the survey sample were currently using a ventilator; of those 78.0% relied on invasive ventilation (a tracheostomy tube) and 22.0% used non-invasive ventilation (a face mask). 6.7% of the sample were past ventilator patients who still attend clinic for follow-up care. 48.4% of the children had severe functional limitations, 21% had some functional limitations, and 2.5% had no functional limitations. 69.8% of the patients had one or

more medical conditions in addition to the diagnosis that required a ventilator (co morbidities).

Information was also collected from the respondents regarding the socioeconomic status and mental health of the child's family (also see Table 4.1). 13.6% of patient families reported that a high school degree or less was the highest level of education anyone in the house has completed, 36.4% reported some college but less than 4 years, and 50.0% reported college graduate or higher. 23.3% of families reported that it is currently a financial struggle, 55.0% reported it is tight but we are doing fine, and 21.7% reported finances aren't really a problem. 25.2% of families spent more than 16 hours a day providing direct patient care to their child, for 36.5% of families the direct patient care contribution was 9-15 hours a day, and 38.3% of families had a daily parent care giving contribution of less than 8 hours. One in six caregivers of children reliant on ventilators screened positive for a probable depressive disorder (16.4%). It is of note that, while below the cutoff for a diagnosable depressive disorder, more than 40% of caregivers reported that in a two week period they felt down/depressed and little interest/pleasure in life "several days" or more.

Table 4.1. Description of a Pediatric Home Ventilator Clinic patient population: patient and family sociodemographics and patient health status

| | N | % |
|---|---|---|
| Number of Survey Respondents | 122 | 100.0% |
| **Patient Demographics** | | |
| *Patient Age* | | |
| 0-2 years old | 26 | 21.5% |
| 3-15 years old | 58 | 47.9% |
| 16-30 years old | 37 | 30.6% |
| *Patient Ethnicity* | | |
| White, non-Hispanic | 92 | 76.7% |
| Black/African-American | 19 | 15.8% |
| Hispanic | 3 | 2.5% |
| Multi racial, Other | 6 | 5.0% |
| *Patient Gender* | | |

| | | |
|---|---|---|
| Male | 66 | 54.1% |
| Female | 56 | 45.9% |
| **Patient Health Status** | | |
| *Primary Diagnosis* | | |
| Primary Diagnosis Lung | 55 | 45.1% |
| Primary Diagnosis Neuromuscular | 33 | 27.0% |
| Primary Diagnosis Airway | 33 | 27.0% |
| Primary Diagnosis Brain | 27 | 22.1% |
| Primary Diagnosis Spinal Cord Injury | 9 | 7.4% |
| Primary Diagnosis Other | 5 | 4.1% |
| *Ventilator Status* | | |
| Currently using ventilator | 115 | 94.3% |
| Invasive ventilator (tracheostomy) | 92 | 78.0% |
| Non-invasive ventilator (face mask) | 26 | 22.0% |
| *Functioning limitations* | | |
| No functional limitations | 3 | 2.5% |
| Some functional limitations | 26 | 21.3% |
| Severe functional limitations | 59 | 48.4% |
| One or more co morbidities | 81 | 69.8% |
| **Family Variables** | | |
| *Parental Education* | | |
| High school degree or less | 16 | 13.6% |
| Some college (less than 4 years) | 43 | 36.4% |
| College graduate (4+ years) | 59 | 50.0% |
| *Family Finances* | | |
| It's a financial struggle | 28 | 23.3% |
| It's tight but we are doing fine | 66 | 55.0% |
| Finances aren't really a problem | 26 | 21.7% |
| *Parent provided direct patient care* | | |
| >= 16 hrs daily | 29 | 25.2% |
| 9 - 15 hrs daily | 42 | 36.5% |
| <= 8 hrs daily | 44 | 38.3% |
| *Caregiver Depressive Disorder* | | |
| Positive Screen on the PHQ-2 | 20 | 16.4% |

Note: Patient population includes current ventilator users N = 115 and past ventilator users N = 7.

Table 4.2 addresses Research Question 2 by presenting the rate of unmet needs for health and supportive services and the frequency of specific barriers to care if the parent reported an unmet need. 56.2% of the surveyed population reported any unmet need. 0.9% reported unmet needs for preventive care and 7.8% reported unmet needs for specialty care. Barriers to care are not presented in Table 3.2 for preventive and specialty

care because of the low rate of unmet need for these services. When asked about unmet need for therapeutic services, 39.4% of parents reported that their child did not receive all the care he/she needed. Of these parents, 38.5% cited waitlist or scheduling problems as a barrier to care, 35.9% reported insurance problems, 28.2% reported it was hard to find a good/qualified therapist, and 20.5% reported a therapist was not available in the area. Almost half of parents, 40.0%, reported an unmet need for home health care. 71.1% reported a lack of adequate staffing, i.e. nursing hours were regularly unfilled, 36.8% reported nurses were not qualified or not trained on pediatric ventilators, and 31.6% reported they did not have enough nursing hours. Unmet needs for medical equipment were reported by 12.0% of parents surveyed. 78.6% cited insurance problems as a barrier to care and 50.0% reported problems with the supply company.

Table 4.2. Unmet needs and barriers to care among a pediatric home ventilator population

| | |
|---|---|
| ***Unmet needs among those who reported a need*** | |
| Any unmet needs | 56.2% |
| Unmet need for preventive care | 0.9% |
| Unmet need for specialty care | 7.8% |
| Unmet needs for therapeutic services | 39.4% |
| Unmet needs for home health care | 40.0% |
| Unmet needs for medical equipment | 12.0% |
| ***Barriers to care if reported an unmet need*** | |
| *Therapeutic services* | |
| Waitlist/scheduling problems | 38.5% |
| Insurance problems | 35.9% |
| Hard to find a good/qualified therapist | 28.2% |
| Therapist not available in our area | 20.5% |
| *Home health care* | |
| Nursing hours were regularly unfilled, lack of staffing | 71.1% |
| Nurses not qualified; not trained for pediatric ventilators | 36.8% |
| Didn't have enough nursing hours | 31.6% |
| *Medical Equipment* | |
| Insurance problems | 78.6% |
| Problems with the supply company | 50.0% |

The rest of the results section addresses Research Question 3: what is the level of unmet need for care coordination assistance within a defined care coordination program and what variables are associated with this unmet need? An unmet need for care coordination assistance was reported by 27.5% of the survey sample. These families either did not receive help coordinating their child's care but reported a need for help (N=10), or received help but reported needing extra help (N=23). Table 4.3 reports the top five locations of care coordination assistance reported by families who received some type of assistance. 90.4% of respondents reported receiving help from the Pediatric Home Ventilator Program, 42.2% received help from their primary care provider's office, 16.9% from another specialty clinic, 10.8% from a case manager, and 9.6% from a therapist.

Table 4.3. Locations of assistance with care coordination among a Pediatric Home Ventilator Program population.

| | N | % |
|---|---|---|
| *Among those who receive some type of assistance* | 83 | 100.0% |
| The Pediatric Home Ventilator Program | 75 | 90.4% |
| Primary care provider's office | 35 | 42.2% |
| Another specialty clinic | 14 | 16.9% |
| Case Manager | 9 | 10.8% |
| Therapist | 8 | 9.6% |

Notes: The top 5 locations of care coordination assistance are reported and are not mutually exclusive.

The percentage of unmet need for care coordination by patient and family demographics and patient health status is presented in Table 4.4. A series of bivariate tests of association revealed that of the eight patient and family variables only two were significantly associated with unmet needs for care coordination: current financial situation and the caregiver depression screen ($p < 0.05$). Unmet need for care coordination was reported by 11.5% of families whose finances aren't really a problem,

24.6% of families who report finances are tight, and by 50.0% of families who report it's a financial struggle. 57.9% of respondents who screened positive for a probable depressive disorder reported unmet need for assistance with care coordination versus 21.8% of respondents with a negative depression screen. A multivariate logistic regression including these two significant patient level variables was conducted to determine independent associations with unmet need for care coordination. Both family financial situation (OR=2.27) and caregiver depression (OR=3.38) were independently associated with unmet need for care coordination, however, due to the small sample size the confidence intervals were large: 95% CI was 1.14-4.51 for finances and 1.12-10.16 for caregiver depression. These results are not reported in the tables and additional multivariate analyses were not conducted given the lack of precision in these estimates.

Table 4.4. Percentage of unmet need for care coordination by patient and family demographics and patient health status.

| | Number with unmet need for care coordination | % |
|---|---|---|
| Population of survey respondents, N=120 | 33 | 27.5 |
| *Child Race/Ethnicity* | | |
| White, non-Hispanic, N=91 | 25 | 27.5% |
| Black/African-American, N=18 | 5 | 27.8% |
| Hispanic, N=3 | 0 | 0.0% |
| Multi racial, Other, N=6 | 2 | 33.3% |
| *Age of the child* | | |
| 0-2 years old, N=26 | 7 | 26.9% |
| 3-15 years old, N=58 | 17 | 29.3% |
| 16-30 years old, N=35 | 9 | 25.7% |
| *Functional Limitations* | | |
| No functional limitations, N=3 | 0 | 0.0% |
| Some functional limitations, N=26 | 5 | 19.2% |
| Severe functional limitations, N=59 | 17 | 28.8% |
| *Type of ventilator* | | |
| Invasive ventilator (tracheostomy), N=92 | 28 | 30.4% |
| Non-invasive ventilator (face mask), N=25 | 4 | 16.0% |
| *Household education level* | | |
| High school degree or less, N=16 | 4 | 25.0% |
| Some college (less than 4 years), N=43 | 9 | 20.9% |
| College graduate (4+ years), N=58 | 18 | 31.0% |

| | | | |
|---|---|---|---|
| *Current financial situation* | | | |
| Finances aren't really a problem, N=26 | 3 | 11.5% | * |
| It's tight but we are doing fine, N=65 | 16 | 24.6% | |
| It's a financial struggle, N=28 | 14 | 50.0% | |
| *Parent provided direct patient care (nursing tasks)* | | | |
| <= 8 hrs daily, N=44 | 8 | 18.2% | |
| 9 - 15 hrs daily, N=41 | 15 | 36.6% | |
| >= 16 hrs daily, N=29 | 7 | 24.1% | |
| *Caregiver probable depressive disorder (PHQ-2)* | | | |
| No depressive disorder, N=101 | 22 | 21.8% | * |
| Positive depression screen, N=19 | 11 | 57.9% | |

Note: Asterisk denotes levels of the independent variable are significantly different by unmet need for care coordination at $P < 0.05$.

Table 4.5 compares the percentage of unmet need for therapeutic and supportive services between families who report adequate care coordination services and families with unmet needs for care coordination. Among the families who reported an unmet need for care coordination assistance, 60.0% reported unmet need for therapeutic services, 63.6% reported unmet need for home health care, and 24.2% reported unmet need for medical equipment. The levels of unmet need for families who received effective care coordination were half that of families with inadequate access to care coordination, 30.9%, 28.1%, and 7% respectively ($p < 0.05$).

Table 4.5. Percentage of unmet need for therapeutic and supportive services by access to adequate care coordination services.

| | *Percentage of unmet need for therapeutic and supportive services* | | | | | |
|---|---|---|---|---|---|---|
| | Therapeutic services | | Home health care | | Medical Equipment | |
| Unmet need for care coordination | 60.0 | * | 63.3 | * | 24.2 | * |
| Received adequate care coordination | 30.9 | | 28.1 | | 7.2 | |

Note. Asterisk denotes levels of unmet need for services are significantly different by access to care coordination at $P < 0.05$

## Discussion

*Summary of results.* Caregivers completed surveys for 122 patients of a pediatric home ventilator clinic. These 122 responses represented 84% of the eligible patient population. The majority of the patient population was white, non-Hispanic (76.7%) and between the ages of three to fifteen years old (47.9%), though patient age ranged from infant to thirty years old. The population consisted of slightly more males (54.1% male versus 45.9% female). Most families included a member who attended some college or was a college graduate (86.4%), but 23.3% of families reported that "it's currently a financial struggle." 25.2% of families provided direct patient care for their children more than 16 hours per day and 16.4% of caregiver respondents screened positive for a probable depressive disorder.

The most common primary diagnoses, meaning the diagnosis that requires a ventilator, was "lung", reported by 45.1% of the patient population. "neuromuscular", "airway", and "brain" were each reported by more than 20% of the population. 78.0% of respondents currently relied on invasive ventilation (tracheostomy) and 22.0% used non-invasive ventilation (face mask). 48.4% of the patient population had severe functional limitations and 69.8% had one or more co morbidities.

Slightly more than half of respondents reported an unmet need for health or supportive services. The most frequently reported unmet needs were therapeutic services, 39.4%, and home health care, 40.0%. There was a low level of unmet need for preventive and specialty care. 27.5%, reported an unmet need for care coordination assistance. Financial struggles and a probable caregiver depressive disorder were the only measured patient and family variables significantly associated with an unmet need

for care coordination. The percentage of families reporting unmet needs for therapeutic and supportive services was twice as high among families with unmet needs for assistance with care coordination activities.

*Profile of the ventilator dependent population.* In response to the lack of state or nationwide data on the prevalence and characteristics of ventilator-dependent children two states, Utah and Massachusetts, conducted a state level censuses of the pediatric population dependent on home mechanical ventilation in their respective states (Gowans et al., 2007). Both of these studies collected basic data on age, gender, diagnostic category, and type of ventilation. However, these studies were limited by their data collection procedures; both conducted retrospective record review of hospital data, home care agencies, and other providers. The present study surveyed caregivers directly, which provided the opportunity to collect the variety of variables necessary to develop a comprehensive demographic and health status profile: patient variables such as functional limitations and co morbidities and family variables such as socioeconomic status, daily parent care-giving contribution and mental health status. This information is crucial for developing appropriate systems of health service delivery and also for investigating correlates of unmet need and barriers to care and indentifying potential points of intervention.

*Unmet need for health and supportive services.* While there is a high level of unmet need among the survey population – 56.5% of children dependent on ventilators reported an unmet need for health or supportive services – the finding of note is the variation in levels of unmet need by type of service. There is a low level of unmet need for preventive and specialty care, 0.9% and 7.3% respectively. However, more than a

third of families report unmet needs for therapeutic services and home health care. The high level of unmet need for services among children dependent on ventilators can be attributed to the special supportive services required due to their complex health care needs and not to a lack of access to preventive and specialty health care services. Given the defined care coordination program in place at the study clinic it is possible that the low level of unmet need for preventive and specialty care can be attributed to this program. Future studies in other ventilator populations are needed to determine the level of unmet need for different types of services at clinics with different or no care coordination programs.

Children with complex health care needs identified by the 2005 National Survey of Children with Special Health Care needs (NS-CSHCN) are a possible population of comparison (Blumberg et al., 2008). Analysis of this dataset by the author, classifying "complex" children according to the coding scheme developed by Hefner (dissertation Chapter 2, 2010) revealed that among this population there was a similarly low level of unmet need for preventive and specialty care (4.0% and 9.0% respectively) and also a high level of unmet need for therapeutic services, 21.8%, and supportive services, 15.5%, though not as high as among the ventilator dependent population. The higher level of unmet need for therapeutic and supportive services among the ventilator population is not surprising given the ways in which the population of children dependent on mechanical ventilation is different from the broader population of children with highly complex chronic conditions such as muscular atrophy, epilepsy or cerebral palsy (Kirk, 1998; Wang & Barnard, 2004). The children in this larger group are heterogeneous in their health care needs and dependence on caregivers. There is less variation in the population

of technology dependent children regarding the need for continuous nursing care – provided either by a nurse or a trained parental care giver, an ongoing supply of expensive equipment, and frequent intense contact with the health care system. The high utilization of this technology dependent subgroup translates into a high level of unmet need for therapeutic and supportive services among the survey sample but the level of unmet need for preventive and specialty care is similar to the national population of children with complex health care needs.

*Access to coordinated care.* Within the ventilator program's defined care coordination program one quarter of families, 27.5%, reported unmet needs for assistance with care coordination activities. These families either did not receive help coordinating their child's care but reported a need for help, or received help but reported needing extra help. The two patient and family variables associated with unmet need for care coordination assistance were current financial struggles and a probable caregiver depressive disorder. Previous qualitative studies of families with ventilator dependent children have found that these families face unique problems among disabled children in terms of family stress and caregiver burden and predictors of family stress include financial problems and a lack of care coordination assistance (Kirk, 1998). This finding from previous research addresses the causal direction of the association between caregiver mental health and lack of care coordination. It may be that instead of caregiver mental health serving as a barrier to receiving care coordination assistance, a lack of access to care coordination assistance, as the result of unmeasured provider or system level barriers, leads to increased stress and poorer caregiver mental health. While there are many excellent qualitative studies of the mental health of caregivers of technology

dependent children, there is a lack of quantitative research on this topic (Wang & Barnard, 2004). The findings of the present study support the hypothesis that access to care coordination may affect caregiver mental health and opens the door to further quantitative research into this topic.

This study also provides support for the hypothesis that access to care coordination is associated with a lower likelihood of unmet needs for care. Among the ventilator clinic sample, the percentage of families reporting unmet needs for therapeutic and supportive services was twice as high among families with unmet needs for assistance with care coordination activities. Hefner (dissertation Chapter 3, 2010) found similar results among the national population of children with complex health care needs; in the 2005 NS-CSHCN the odds of reporting any unmet needs for care were 3.16 greater for families without adequate care coordination. Hefner (dissertation Chapter 2, 2010) found that high complexity CSHCN report logistical barriers to care not prominently reported by the low/moderate complexity population: clinic not available in the patient's area, transportation problems, and inconvenient clinic times. Longitudinal studies of care coordination programs have found that receiving care coordination assistance ameliorates the logistical barriers reported most frequently by families with high complexity CSHCN (Palfrey et al., 2004; Wood et al., 2009), which at least partially explains the striking reduction in unmet need among those who receive adequate care coordination assistance.

*Limitations.* One limitation of this study is the lack of precision in the analysis due to the small sample size. It was not possible to conduct multivariate analysis, and even bivariate tests of association were subject to large confidence intervals. It is possible to make statements about which variables are significantly associated with outcomes of

interest such as unmet need for services and care coordination assistance, but there is a lack of precision in these estimates. Given this limitation, the aim of this study is to serve as a descriptive report of a population of ventilator dependent children and to identify significant variables of interest for future investigation with larger sample sizes.

This paper is subject to another limitation. Though the study site serves ventilator dependent children throughout the state of Michigan from diverse economic backgrounds, the study population may not be representative of ventilator dependent populations who attend clinics at other health systems and/or in other geographic locations. Recommendations for policy and practice that result from this study will need to be tailored to the target population and evaluated in diverse practice settings.

*Conclusion.* Due to improvements in perinatal technology and the treatment of childhood trauma and disease the number of children dependent on mechanical ventilation is growing. These children are a vulnerable population by virtue of their chronic disability and are therefore at greater risk for health disparities and access barriers. Despite this fact there is little known about the experiences of children on ventilators within the health services system. This is the first study, to my knowledge, to identify the types of unmet needs families' caring for a child on a ventilator face and to determine the correlates of access to care coordination. Families reported a high level of unmet need for therapeutic and supportive services, while reporting a low level of unmet need for traditional preventive and specialty medical services. Within the defined care coordination program available at the study site a third of families reported an unmet need for care coordination assistance. Current financial struggles and a probable caregiver depressive disorder were the only measured patient and family variables

significantly associated with an unmet need for care coordination. The percentage of families reporting unmet needs for therapeutic and supportive services was twice as high among families with unmet needs for assistance with care coordination activities, providing support for previous findings among CSHCN that a lack of care coordination assistance is associated with unmet needs for health and supportive services. This study raises many interesting directions for future research among the national ventilator clinic sample and points to the need for more rigorous comparative studies.

# Chapter 5. Conclusion

The broad objective of this dissertation research was to examine the health care system experiences of a vulnerable population: children with complex special health care needs. Prior to the present study there was a lack of a consistent operationalization of complexity; it was generally considered to be a function of the child's ongoing healthcare needs, including the required number of providers, the diversity of types of providers, and the frequency of provider contacts ((Agency for Healthcare Research and Quality, 2008; Bramlett et al., 2008; Kirk, 2008). Children with "complex medical needs" (defined based on one or more of the variables listed in Table 2.1) have a higher likelihood of negative outcomes than children whose needs are less complex (including unmet need for medical, therapeutic and/or mental health services, barriers to care, lack of care coordination, and negative financial impacts on the family) (Benedict, 2008; Dusing et al., 2004; Ganz & Tendulkar, 2006; Inkelas et al., 2007; Inkelas et al., 2007; Kane et al., 2005; Nageswaran et al., 2008). Despite this consistent association previous research into the general population of children with special health care needs (CSHCN) has failed to identify high complexity children as a distinct subgroup and explore what specific access barriers these children face and what aspects of the health system may improve access among this group.

Chapters 2 through 4 in this dissertation had methodological and empirical aims designed to address these gaps in the current literature, with the goal of informing policy discussions surrounding the heterogeneous group of CSHCN and how the health care

system can best meet their needs. The goals of this final chapter are to provide an overview of the range of government programs and agencies that currently provide services for children with special health care needs in order to anchor the following policy discussion. In this overview I specifically outline the models of care coordination for CSHCN that have been proposed and evaluated and highlight the policy discussion surrounding these models. I then briefly summarize the findings of Chapters 2 though 4 – highlighting significant contributions to the literature – and discuss the implications of these findings for policy and future research in light of the current system of care for these children.

A review of the agencies and programs who provide services to CSHCN is best summarized by the conclusion of the 2001 Institute of Medicine Crossing the Quality Chasm report which cited the complexity of the system of care for children and adults with chronic illness as a major impediment to improving both processes and outcomes of care (McDonald et al., June 2007). This stems from the fact that in addition to primary and specialty care CSHCN receive educational, developmental and support services from many agencies and programs (Wood et al., 2009). This results in children with special health care needs becoming embedded in multiple systems of care that include health insurance plans, public supports, community-based programs, and a variety of specialized providers (Krauss, Wells, Gulley, & Anderson, 2001).

The Maternal and Child Health Bureau (MCHB) is the main government agency that funds, oversees and evaluates programs for CSHCN. The mandate of this government agency is to improve the health of all women and children with a specific objective relating to CSHCN: support the development and implementation of

comprehensive, culturally competent, coordinated systems of care for children with special health care needs (Health Resources and Services Administration, Maternal and Child Health Bureau, 2010). Each state is mandated to have a Title V program that uses MCHB block grant funding to among other things, train providers and provide support services for children with special health care needs. The nature of the block grant funding model means that there are significant between-state differences in the types of programs available to CSHCN. Generally, Title V programs provide four levels of services: direct health care services, enabling services (e.g., transportation, family support services, purchase of health insurance), population-based services (e.g. screenings, immunizations, nutrition outreach), and infrastructure building services (e.g. needs assessment, evaluation, coordination) (Champions for Inclusive Communities, 2010). States are free to determine which programs and services are implemented within these four levels based on the needs in each state and are required to submit reports which include performance and outcome indicators in their applications for future funding. Through this mechanism the federal MCHB retains oversight of state Title V services for CSHCN.

This dissertation establishes that CSHCN currently receive care coordination from a variety of sources, therefore, a review of the models that have been proposed and studied for CHSCN can provide an understanding of the type of care coordination services children are currently receiving and inform policy prescriptions to expand care coordination services for children with high complexity health care needs. The current model of care coordination all CSHCN have access to is implemented at the state level. Within each state Title V agency there is a program to provide health care coordination to

CSHCN. Most states offer care coordination by nurses physically located in state agencies and patients are assigned to a nurse care coordinator by a variety of criteria including geographic area or condition (Wood et al., 2009).

Resent research has distinguished between this type of care coordination, referred to as "external," and "internal" programs in which the nurse is physically located in the provider's office (McAllister et al., 2007). These internal programs tend to be linked to a particular model of care provision, the "medical home" (Wise, Huffman, & Brat, 2007). The definition of a medical home can be summarized as a physician-led, primary care practice providing comprehensive care for children and families (Council on Children With Disabilities, 2005). In addition to "external" models provided by Title V agencies, CSHCN and their families can have access to additional "internal" care coordination programs through primary care providers' offices, specialty clinics, specialty-primary care partnerships (Antonelli et al., 2008; Gordon et al., 2007; Liptak et al., 1998; Stille & Antonelli, 2004). Wood et al. (2009) conducted a longitudinal study of six pediatric practices comparing external Title V care coordination, what he referred to as agency-based, versus internal, or practice-based, care coordination led by an on-site nurse coordinator. They found that the practice based model resulted in increased family satisfaction and reduced barriers to care, with the effect being strongest among those with severe health problems. The authors point to this finding as evidence of the benefits of practice-based care coordination over agency-based models. There have been other recent positive evaluations of the practice-based model of care coordination (Lawson, Bloom, Sadof, Stille, & Perrin, 2010; Martin et al., 2007)and prominent policy papers

have rejected the agency-based model in favor of medical home based care coordination programs (Antonelli, McAllister, & Popp, 2009; McAllister et al., 2007).

One recent study conducted by Farmer et al. (2010) proposed and evaluated a new "consultative model of care coordination" for CSHCN which merges the agency and provider models by providing an external care coordinator who directly consults with the child's medical home. The external coordinator – called a Family Support Specialist, is responsible for a panel of CSHCN at multiple primary care clinics within a geographic area. The coordinator's duties include providing care coordination services (visiting children's homes, creating a care plan, direct advocacy, phone follow-up) and consulting with each child's primary care doctor. A before and after evaluation of program participants revealed a decline in unmet needs, improved satisfaction with care coordination, and improved child health and family function outcomes. The authors concluded that the intervention off-set the provider barriers to care typically identified by physicians, such as a lack of time, staffing and reimbursement (Antonelli & Antonelli, 2004; Davidson et al., 2002), and propose that this model could be adopted by agency-based service coordinators such as Title V programs which currently do not consult directly with physician's offices.

Wood et al. (2009) found that having a care coordinator fully integrated into the primary care practice has benefits over the agency model, but most practices do not serve a large enough number of CSHCN to justify the expense. The intervention evaluated by Farmer et al. (2009) was funded by a Medicaid Managed Care Organization (MCO), which is another location of potential agency-based coordination services. There is currently a lack of reimbursement mechanisms for provider based, internal, care

coordination activities. However, both Title V agencies, and insurance companies such as Medicaid MCOs, currently provide care coordination services and therefore a model such as the "consultative model of care coordination" that merges agency-based services with a medical home approach may be the most feasible financially under the current health financing system.

*Summary of Chapter 2 and significant contributions.* Chapter 2 developed a two-variable measure to operationalize complexity through a factor analysis of seven variables previously used to measure the latent construct of complexity of health care needs. Applying this measure to the 2005 NS-CSHCN provided support for the main thesis of this paper - children on the complex end of the CSHCN continuum have needs that differ markedly from the broader group. Specifically, high complexity CSHCN presented a different diagnostic profile and reported an alarmingly high level of parent-reported unmet need when compared to low to moderate complexity CSHCN. High complexity children also reported unique barriers to care. More than 1 in 100 U.S. children, or 1.3% of U.S. kids, fall into this vulnerable group (based on 2006 U.S. Census Bureau data). Comparing the demographics and diagnoses of high complexity CSHCN to low/moderate complexity CSHCN, high complexity CSHCN were significantly more likely to be poor, male, and lack adequate insurance. The most striking differences in diagnosis rates were for autism, mental retardation, and cerebral palsy, with the vast majority of children diagnosed with these three conditions coded into the high complexity group. High complexity CSHCN were significantly more likely to report a need for services, particularly therapeutic services (94.5% versus 34.9%). Among those who reported any need for services, high complexity children were significantly more likely to

report unmet needs (27.4% versus 9.0%). In a multivariate model, complexity was more strongly associated with unmet needs than inadequate insurance or poverty. When asked about barriers to obtaining needed preventive and specialty care the low to moderate complexity population predominantly reported financial barriers related to inadequate insurance and cost while the high complexity population reported logistical and provider barriers.

Chapter 2 represents an innovative contribution to previous research by proposing that children with complex health care needs may have needs that differ markedly from the broader group of CSHCN, and as such should be the focus of independent studies and policy discussions. This is the first study to identify the high complexity population with the aim of describing this vulnerable group. It does appear that these children have a different demographic profile, a higher level of unmet need, and report different barriers to care. Previous research has simply stratified by complexity to control for its effects of outcomes of interest without considering high complexity children as a distinct group. The framing of these children as a distinct policy group has important implications for research and policy development, which will be discussed in the following section, and is the single most innovative aspect of this dissertation research.

In addition to proposing a new policy framing, this chapter makes a significant contribution to research methodology by developing and validating a parsimonious two-variable measure of complexity that will allow for consistent identification of the high complexity subgroup. Previous studies have used a variety of variables to stratify by complexity and it was not clear whether these variables were even identifying the same population. The factor analysis and validation tests conducted in Chapter 2 found that it

is possible to identify the population of high complexity children with special health care needs using a parsimonious, valid set of variables that represent a single latent construct of highly complex health care needs.

*Chapter 2 research and policy prescriptions: Identification of the high complexity group.* The next step in the development of this measure is to conduct further validity studies, including exploring the sensitivity and specificity of this measure. This task is more difficult than for other similar measures, e.g. mental health screening tools, because there is no preexisting accepted definition of the construct. One possible study design in the provider's office is to use existing medical records to select a high complexity sample from a single pediatric clinic, or a series of pediatric clinics within a health system, and compare this sample to the professional qualitative assessments of a team of doctors. Or, also in the clinic setting to expand the definition of complexity to include three or four of the variables used in the factor analysis and compare that larger sample to the two variable measure proposed in this study. Both of these study designs would provide more information on the sensitivity and specificity of this measure. These validity studies should include an investigation of the test/re-test validity of this measure. High complexity children with special health care needs are a dynamic population whose level of service need and disease status can fluctuate over time. A test/re-test design would allow for a determination of just how fluid, or static, the population identified by the measure is. These types of investigations should be preformed before this measure is employed in a practice setting where complete identification of the population is critical.

The two-variable measure does capture the vast majority of the variation in the construct of complexity and is therefore an important tool for research where the goal is

to identify a representative sample of high complexity children on which to analyze research and policy questions. The two variables included in this measure – count of conditions from the CSHCN screener and severity of functioning limitations – are available in the 2001 and 2005 National Survey of Children with Special Health Care Needs. This is the most prominent, nationally representative survey of CSHCN and is the main source of secondary data analysis on CSHCN in the health services literature. Future primary data collection efforts should include these two variables and if there is a financial or logistical limit to the number of questions included these two variables can be prioritized over the other health status and severity variables typically included because this study's factor analysis revealed that the two variable measure captures the majority of the variation in these other variables.

Development of this standard definition of high complexity may affect the organization, delivery and financing of services for children with special health care needs by providing an alternative to classifying CSHCN based on diagnoses. Diagnoses groups are the focus of biomedical research and are therefore important labels in health services at the individual patient and clinic level in terms of prognosis and treatment goals. However, diagnoses groups include children of varying severity and level of service need and are not as useful when considering health services policy questions related to unmet needs for care and care coordination among multiple providers and services. For example, this study found that three disorders, attention deficit disorder, mental retardation, and mental health problems, have a prevalence of over 50% in the high complexity group. Policy solutions could involve strengthening the parts of the health system that address these disorders specifically. However, the majority of high

complexity CSHCN have multiple co morbidities and report unique barriers and unmet needs that cross the barriers of particular specialties and diagnoses. Identifying children based on the two variable measure of complexity developed in this paper allows researchers and policy makers to identify children with similar needs for services and potential barriers to care across diagnosis groups. This approach will reach a larger population of CSHCN than focusing on single conditions. It is important to note, as mentioned above, that the high complexity population is dynamic and employing the two-variable measure of complexity will identify high complexity CSHCN for the purposes of research or within a practice setting at one point in time and the population under study will need to be re-evaluated for movement in and out of the high complexity group. The future validity studies discussed in the previous section will serve to inform the frequency with which the population will need to be reevaluated. .

*Chapter 2 research and policy prescriptions: unmet needs and barriers to care.* An analysis of the 2001 version of the NS-CSHCN assessed the top barriers to care among children who reported delayed or foregone care (Huang et al., 2005). The most frequently reported barriers were financial – results identical to the low to moderate complexity population in the present study – and only a small percentage reported the logistical and provider barriers that were found to be top barriers to care among the high complexity subgroup of CSHCN. Therefore, future research that does not conduct separate analyses for high complexity children will fail to identify these important differences and this may lead to policies aimed at reducing barriers to care that do not benefit high complexity children and their families. Specifically, interventions aimed at increasing insurance coverage as a method of reducing unmet needs for health services,

such as the 2010 “Patient Protection and Affordable Care Act” recently signed into law by President Obama, may reduce barriers to care among the general population of CSHCN by focusing on financial barriers to care; however, families with high complexity children may not see a reduction in their unmet needs for care because this policy solution does not address the unique logistics and provider barriers to care these families face: geographic access, doctor knowledge, inconvenient clinic times.

*Summary of Chapter 3 and significant contributions.* The results presented in Chapter 3 provide support for the hypothesis that receiving adequate assistance with care coordination is associated with reductions in unmet needs for medical, therapeutic, and supportive services within the population of children with complex health care needs. However, only 35.6% of high complexity children with special health care needs receive effective care coordination compared to 62.1% of low to moderate complexity CSHCN. Among a list of patient and family sociodemographic characteristics and four disorders prominent in the high complexity population, inadequate insurance is the only individual level variable that is independently associated with unmet need for care coordination.

This finding represents a significant contribution to the literature because it may be an indication that variables at the health services rather than the individual level are important factors in the high level of unmet need for assistance with care coordination among children with complex health care needs. Previous studies have found provider and system level barriers to implementing care coordination programs for children with complex needs. Specifically, doctors report that it is particularly difficult to coordinate care for their most complex patients, who average a higher number of encounters and necessitate a larger amount of time spent in care coordination activities (Antonelli &

Antonelli, 2004; Davidson et al., 2002). When examining issues of access to care coordination Chapter 3 reveals that it is important to examine barriers at all levels of the health services system, in addition to the need to examine access among the high complexity group separate from the broader population of CSHCN.

*Chapter 3 research and policy prescriptions: defining adequate care coordination and its correlates.* One limitation of this dissertation research is the global definition of "adequate care coordination". In the NS-CSHCN 2005 this is a parent reported measure and does not address the type or location of the services the family receives. Despite the current policy focus on care coordination, as discussed in the review above, the type and level of assistance that a child with special health care needs receives varies across health systems and families. One important next step toward assessing the different types of care coordination programs currently available to CSHCN is to collect more specific information in national surveys. Specifically, the survey questions in the 2005 NS-CSHCN do not differentiate between assistance from a primary care provider or a specialist's office. There is debate in the literature among those who support the practice-based model of coordination regarding whether care coordination programs are most effective when facilitated by the pediatrician, a specialist clinic, or a primary care/specialty partnership (Alexander et al., 2005; Graham, 2008; McAllister et al., 2007; Sutton et al., 2008). In future versions of the NS-CSHCN the question wording should be altered to include a choice between pediatrician's office and specialist's office in order to provide for descriptive statistics to inform this current policy debate.

Another important implication of this dissertation is the evidence that while care coordination is significantly associated with unmet needs for care among high complexity

CSHCN, there is a low level of access to care coordination assistance among these families. Leading child health policy advocates, including the American Academy of Pediatrics, propose care coordination programs as a solution for reducing barriers to care and unmet need among children with special health care needs (CSHCN) (Council on Children With Disabilities, 2005; Lipkin et al., 2005; McAllister et al., 2007) and this paper provides support for this policy statement. Given that inadequate insurance is the only sociodemographic variable associated with unmet need for care coordination, there is a need for future research into what aspects of insurance coverage are associated with increased access to care coordination because many of the families that were coded as having "inadequate insurance coverage" did have insurance in the past year but reported either gaps in coverage or underinsurance problems such as a lack of coverage for needed services or high out of pocket costs.

In 2010 the "The Patient Protection and Affordable Care Act" became law and when enacted will expand insurance coverage to families who may have gaps in insurance coverage or have trouble getting coverage because of their child's pre-existing condition. This law may slightly reduce the high level of unmet need for care coordination among high complexity CSHCN if a family's unmet need is caused exclusively by a lack of insurance coverage. However, this law does not directly address the other causes of underinsurance, such as out of pocket costs and coverage of specific needed services. Research is needed into which aspects of insurance increase access to care coordination and then changes in health insurance policy can be considered that would have a greater likelihood of improving access. This research could be conducted on currently available secondary data sources by assessing the independent effects of the

separate elements of the MCHB "inadequate insurance coverage" variable on unmet needs for care coordination.

*Chapter 3 research and policy prescriptions: care coordination interventions for high complexity CSHCN.* High complexity children report unique barriers and unmet needs that cross the barriers of particular specialties and diagnoses and identifying children based on the two variable measure of complexity developed in this paper allows researchers and policy makers to identify children with similar needs for services and potential barriers to care across diagnosis groups. This has implications for policy and health care delivery related to care coordination because interventions can be tailored toward this unique group instead of by diagnostic group. Implications for organization of services include targeted delivery of enhanced care coordination services directed towards high complexity children identified using this measure; the patients for whom care coordination assistance has the greatest positive affect (Palfrey et al., 2004; Wood et al., 2009).

This could be implemented through adoption of the "consultative model of care coordination" (Farmer, Clark, Drewel, Swenson, & Ge, 2010) by state Title V agencies for only high complexity CSHCN while the remaining CSHCN population continues to receive the traditional agency based model of care coordination that does not consult directly with the child's medical home. Research has shown that practice based participation in care coordination has significantly greater positive effects for those with the most severe conditions (Wood et al., 2009). The development of the measure of complexity makes this targeted intervention possible and it is feasible financially because state Title V agencies already have the finances to provide care coordination services and

have the flexibility of block grant funding to tailor the program to include this targeted intervention

*Summary of Chapter 4 and significant contributions.* Chapter 4 was a descriptive analysis of children dependent on ventilators and the health services system. Data for this study was collected through a survey of caregivers whose children attend a pediatric home ventilator clinic. Responses to this survey revealed a high level of unmet need for therapeutic and supportive services, but a low level of unmet need for traditional preventive and specialty medical services. Within the defined care coordination program available at the study site a third of families reported an unmet need for care coordination assistance. The percentage of families reporting unmet needs for therapeutic and supportive services was twice as high among families with unmet needs for assistance with care coordination activities, providing support for previous findings among CSHCN that a lack of care coordination assistance is associated with unmet needs for health and supportive services. Current financial struggles and a probable caregiver depressive disorder were the only measured patient and family variables significantly associated with an unmet need for care coordination. These findings support the hypothesis that access to care coordination may affect caregiver mental health.

Chapter 4 makes two important contributions to the literature. First, this study is unique among previous studies of the demographic profile of ventilator dependent children because a variety of individual and family variables were collected, in addition to traditional biomedical variables. This information is crucial for developing appropriate systems of health service delivery and also for investigating correlates of unmet need and barriers to care and indentifying potential points of intervention. In addition to the

demographic information, Chapter 4 is the first study, to my knowledge, to identify the types of unmet needs families' caring for a child on a ventilator face and to determine the correlates of access to care coordination. While the level of unmet need for services was high, over 50%, this broad category masked different levels of unmet need by type of health services. It appears that this vulnerable group of highly complex children had few unmet needs for preventive and specialty care but a high level of unmet need for therapeutic and supportive services. This has implications for future policy and program implementation, which will be discussed in the following section.

*Chapter 4 research and policy prescriptions.* Specific recommendations for future research into the ventilator dependent population that stem from this research are to conduct more descriptive research at home ventilator clinics in other states to determine if the same individual and family variables are associated with unmet needs for care in other settings. Current descriptive research is limited by the mode of data collection, retrospective chart reviews. Future data collection efforts should collect child and family sociodemographic variables, unmet needs, and barriers to care by directly surveying caregivers. This research is imperative given the increasing prevalence of children reliant on home ventilation and the high level of unmet needs for therapeutic and supportive services found among this population.

Additionally, the descriptive results reported in this study support the implementation of experimental study designs with before and after measurement of access and unmet needs within a single clinic site. Comparative studies of clinics without care coordination programs and/or various types of care coordination programs – agency versus practice based models – are also needed to further explore the possible benefits of

care coordination programs that are revealed by the present study. While initially the study sites should be other home ventilator clinics another direction for future research is to assess the themes of unmet need for services and care coordination in other technology dependent populations.

*Summary of a future research agenda.* Overall, the findings presented in Chapters 2 through 4 suggest that children with high complexity special health care needs should be the focus of independent studies and policy discussions. Compared to children with low to moderately complex special health care needs, high complexity children present a unique diagnostic profile and report a high level of unmet needs for therapeutic and supportive services and care coordination assistance. The families also face unique barriers to care. Specifically, families with high complexity children frequently report logistical and provider level barriers not commonly reported among the remaining CSHCN population. When results are not reported separately for high complexity CSHCN the opportunity is missed to identify these unique barriers and to assess their association with the disproportionately high level of unmet need among high complexity CSHCN.

The next step in the development of the two variable measure of complexity proposed in this dissertation is to conduct further validation studies, including exploring the sensitivity and specificity of this measure. Given that the two-variable measure does capture the vast majority of the variation in the construct of complexity it is an important tool for research where the goal is to identify a representative sample of high complexity children in order to explore research questions. The two variables included in this measure – count of conditions from the CSHCN screener and severity of functioning

limitations – are available in the 2001 and 2005 National Survey of Children with Special Health Care Needs. This is the most prominent, nationally representative survey of CSHCN and is the main source of secondary data analysis on CSHCN in the health services literature, therefore, future studies using this dataset could immediately separate analysis by complexity using this measure. This will allow for the appropriate identification of unique barriers to care in the high complexity population.

Development of this standard definition of high complexity has implications for policy and health care delivery related to care coordination, specifically, care coordination services can be directed towards high complexity children identified using this measure; the patients for whom this assistance will have the greatest affect (Palfrey et al., 2004; Wood et al., 2009). This could be implemented through adoption of the "consultative model of care coordination" (Farmer et al., 2010) by state Title V agencies for only high complexity CSHCN while the remaining CSHCN population continue to receive the traditional agency based model of care coordination. Research has shown that practice based participation in care coordination has significantly greater positive effects for those with the most severe conditions (Wood et al., 2009). The development of the measure of complexity makes this targeted intervention possible and it is feasible financially because state Title V agencies already have the finances to provide care coordination services and have the flexibility of block grant funding to tailor the program to include this targeted intervention

In addition to expanding the provision of care coordination to children with complex health care needs, it is crucial to investigate avenues to reduce barriers to existing care coordination services. Given that inadequate insurance was the only

measured barrier associated with unmet need for care coordination there is a need for future research into what aspects of insurance coverage are associated with increased access to care coordination because many of the families that were coded as having "inadequate insurance coverage" did have insurance in the past year but reported either gaps in coverage or underinsurance problems such as a lack of coverage for needed services or high out of pocket costs. This research could be conducted on currently available secondary data sources by assessing the independent effects of the separate elements of the MCHB "inadequate insurance coverage" variable on unmet needs for care coordination.

As outlined above, this dissertation research has important implications for policy and future research; the most important being that children with high complexity special health care needs should be the focus of independent studies and policy discussions. The framing of this vulnerable population as an independent policy group will allow health services researchers to further explore the unique barriers to care faced by these children and their families. Focusing on high complexity children will also allow health policy professionals to consider interventions to reduce barriers to care that are tailored to the unique needs of this population.

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